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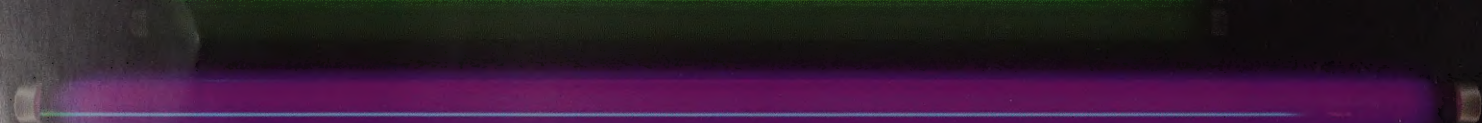
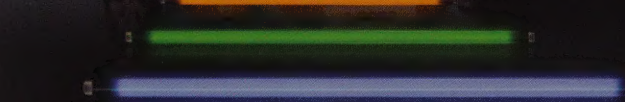
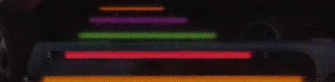
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# editorial

## When personal goes public

Chris Woodhead has always been something of a maverick and has often seemed too outspoken for many people's taste. His latest pronouncements on his diagnosis of motor neurone disease (MND) will do nothing to dispel or re-shape that image, particularly among us as disabled people.

People react to the onset of impairment, to becoming disabled, in all sorts of ways. Sometimes, for those of us who've been what and as we are since birth, some of those reactions can seem both alien and alienating and, at the very least, difficult to understand. On the other hand, taking a judgemental stance towards adventitiously disabled people can make us appear to be anything from presumptuous and high-handed to sanctimonious or just plain callous.

So, the first thing for me to be absolutely clear on is that any decision Chris Woodhead makes about the continuance of his life or the way in which he might end it, following the announcement of his diagnosis, is entirely personal.

What seems to me to be deeply unhelpful is his decision to put that highly

personal decision firmly in the public domain.

For a start it's unhelpful to people who may be living with a similar diagnosis. If they have reached the same conclusion about the worth of their life, then what Chris Woodhead says will merely act as a fixer to that image of themselves. There may too be people who, having been diagnosed with MND themselves, have found some sort of hope and quality of life, an accommodation for living with their newly acquired status.

**“What seems to me to be deeply unhelpful is his decision to put that highly personal decision firmly in the public domain”**

But most of all, the expression of such personal views as public statements risks re-enforcing the more generally negative perceptions of the wider community of disabled people. People really don't need this sort of encouragement to regard our lives as worth less or even worthless.



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# newsview

## Hate crime: ministerial concern but no commitments

Ahead of the launch of the Government's hate crime action plan, **Ian Macrae** finds Home Office Minister Alan Campbell full of concern and the will to address issues, but disappointingly light on commitments

It was August last year when Scope, *Disability Now* and United Kingdom Disabled People's Council (UKDPC) jointly launched their report on disability hate crime *Getting Away With Murder*.

Since then, those and other organisations in the Disability Hate Crime Alliance have been awaiting the Government's response.

Following a meeting with campaigners, Alan Campbell, the minister whose responsibilities include hate crime, is keen to show that this is an issue that's firmly on his and the Government's radar.

"The fact that people are chosen as victims because of their disabilities makes it particularly obscene and entirely unacceptable," he says, and has clearly taken on board the issues raised in the report and in our disability hate crime coverage.

**“Where it's clear that a crime was motivated by hate, he's reluctant to interfere in what he sees as a Ministry of Justice matter”**

"I accept that a great deal more needs to be done. It's about changing attitudes. It's about making sure that the police take into account the circumstances of individual victims and recognise incidents as potential hate crimes. But it's also about building confidence for victims themselves to come forward and report incidents as hate crimes."

His concern is heart-felt. He's less impressive when it comes to firmer policies and initiatives.

For example, while recognising the need for more police training in the recognition and identification of likely hate crimes, and welcoming the publication by the Association of Chief Police Officers (ACPO) on hate crime of all sorts, there's little that's solid from the Government directly.

And on the question of making it compulsory for judges to give longer sentences where it's clear that a crime was motivated by hate, he's reluctant to interfere in what he sees as a Ministry of Justice matter.

"We have to be sure that the prosecuting authorities and the judiciary are given the independence to do



what they have to do," he says. And his best offer is equivocal: "I certainly wouldn't rule out taking action on this issue, if that's the conclusion we reach."

Similarly, on the question of establishing the actual extent of disability hate crime through a prevalence study, the minister is once again in a not-ruling-out mode rather than a

commitment mode.

"We've just introduced hate crime as a statutory key performance indicator, so let's see what that shows up. I certainly wouldn't rule out a study, but I'm not in a position to commit to that."

Probably the best that can be said about the Government's approach to properly tackling disability hate crime is that the jury is still out.



# newsupdate

## Celebs back Mind's strategy call



Spraying it like it is: left to right, Alistair Campbell, Lord Bragg, Stephen Fry and Matt Wilkinson

### Cathy Reay

Former No 10 Press Chief, Alistair Campbell and actor Joe McGann are among celebrities who've lent their support to a call for a Government strategy on men's mental health.

The call has been made by Mind in the light of new research that shows that almost 40 per cent of men in the UK are worried or feel low because of the recession.

The leading mental health charity made the call after

finding that 2.7 million men in England currently have a mental health problem and that middle-aged men have the highest suicide rate in England and Wales.

Mind unveiled the research in *Men and Mental Health: Get it off Your Chest*, which also found that 31 per cent of men in the UK are more likely to feel embarrassed about seeking help for mental distress.

The research showed a link between depression in men and the current econ-

omic climate as the top three issues playing on men's minds are money, job security and work.

Speaking to *Disability Now*, Alistair Campbell said: "Many people, especially men, find it very hard to be open about mental fragility. They see it as a sign of weakness to ask for help, or they cover it with drink or drugs or behaviour generally likely to end in tears.

"I certainly support Mind's call for a Government specific mental health

strategy for men tailored to their needs. They have one for women and children so why not men?"

Joe McGann told *Disability Now* that, as a man, he has found it difficult to be open about his emotions. "When I was experiencing depression I tried to avoid people, even my close family and friends, and when I did speak to people I'd put on a brave face. Men are supposed to shut up and get on with it."

Others supporting the call include Lord Bragg, Stephen Fry and Matt Wilkinson of radio station Heart FM.

Mind's chief executive Paul Farmer said: "Being a breadwinner is something that's still crucial to the male psyche, so if a man loses his job he loses a large part of his identity, putting his mental well-being in jeopardy.

"There's an urgent need here that the Government has to address."

Care Services Minister Phil Hope said: "We've commissioned the Men's Health Forum to identify specific mental health needs of men and we expect its report this summer.

"It will build on the findings from Mind and show us what more needs to be done to improve mental health support for men in particular."





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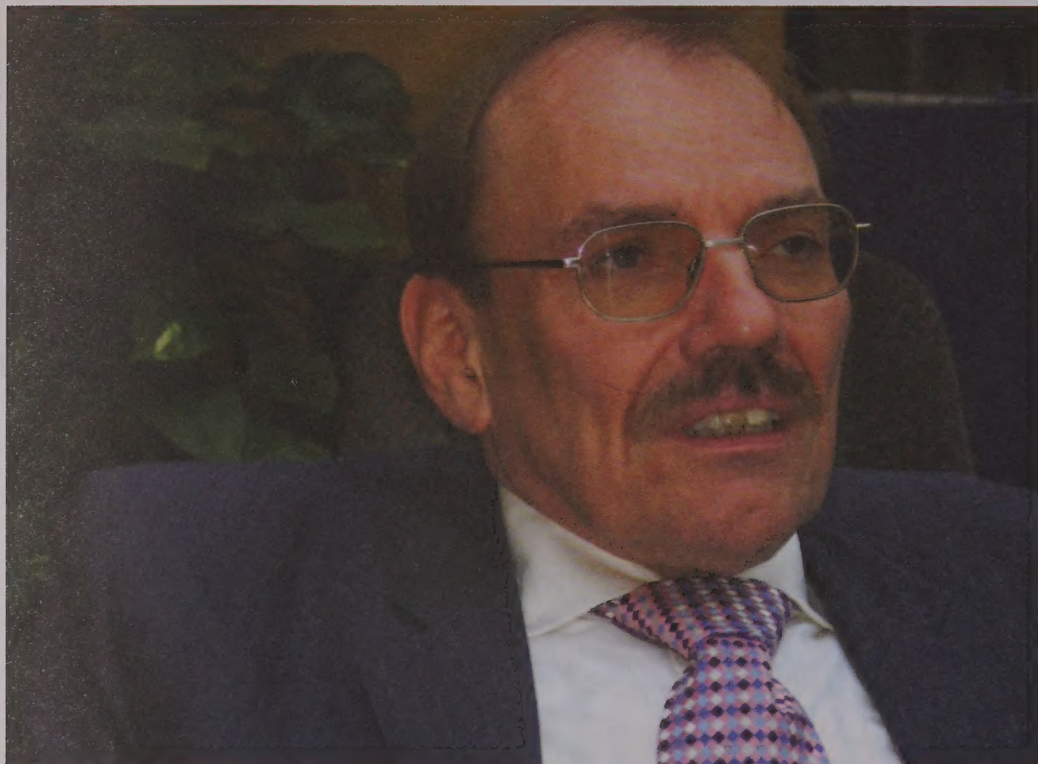
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# newsupdate

## 'Equality bill disappointing' says Sir Bert



JAMIE TROUNCE

Veteran disability rights campaigner Sir Bert Massey (pictured, above) has told *Disability Now* that the Government's new equality bill will dilute disabled people's rights.

He also says that the new bill, which has now begun its journey through Parliament, fails to deliver on beefing up existing disability discrimination legislation.

"This is not a new and enhanced Disability Discrimination Act (DDA)," he said. "It is mainly a consolidation bill used to incorporate different acts of Parliament into a single bill, with the

objective of making it easier to understand and follow.

"It will repeal the 1995 and 2005 DDAs and incorporate their provisions into what will become the Equality Act 2010.

"But life is seldom so simple. The Disability Rights Commission (DRC) had recommended additions to the DDA and it was hoped that they would be included in the new bill. That hope has been in vain, so there is still much for disabled people to campaign on.

"The DRC called for pre-interview questions on disability to be banned

when people apply for a job, as this is often used to deny a person an interview. The bill is silent on this.

**“Pre-interview questions are often used to deny a person an interview and the bill is silent on this”**

"It would also have been good if the payments awarded to people who have been discriminated against when buying goods or services had been increased, so that it is

always more expensive to discriminate than not to. Alas, discrimination will remain the cheap option for some service providers.

"With any consolidation bill there is a danger that some provisions will be watered down, and that people will have fewer or less enforceable rights as a result.

"For example, under the DDA there is a requirement to remove barriers. The new bill proposes changing this to 'avoiding disadvantage'. This phrase might be weaker than the current law."

Sir Bert also fears that the single equalities approach will mean disabled people are less involved in policy decisions that affect us.

"One of the major changes introduced in regulations that followed the 2005 Act was the requirement for public authorities to involve disabled people when setting policies that affected them. The bill introduces a single equality duty and we must ensure that disabled people's involvement isn't lost in the quest to standardise equality legislation.

"Disabled people and their organisations need to be ever vigilant that a bill that is broadly welcomed is not allowed to move disability rights backwards."



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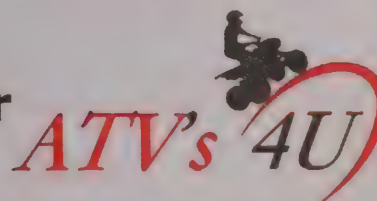
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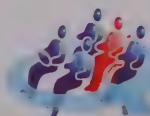
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# ruthpatrick

# Cold **blast** of reality



After too many months of cold weather and dark nights, summer seems to have finally arrived. But, as **Ruth Patrick** points out, winter will be back all too soon and it is vital to spend some of the summer considering the on-going issue of fuel poverty and disabled people if we're not to see again thousands struggling to afford to heat their homes

**E**arly on in New Labour's reign, a system of Winter Fuel Payments (WFP) was introduced for those aged 60 and over. The value of these payments has increased steadily and last year they were worth between £125 and £400, depending on age and household circumstances. All households with an elderly member receive a WFP, regardless of income. Thus, entitlement to a WFP encompasses the retired millionaire, the expat living in Spain, and the pensioner struggling to make ends meet on the poverty line.

It has long been argued by the disabled community that these payments should be extended to include those disabled people in receipt of high-level Disability Living Allowance (DLA) due to mobility impairments. In recent research by the Leonard Cheshire charity, disabled people's particular vulnerability to fuel poverty was highlighted alongside



GEORGIOS KOLLIDAS

the dangerous impact of such poverty where the cold aggravates individuals' impairments. Receiving a WFP could help prevent disabled people from suffering from fuel poverty and would ensure that vulnerable people are not consigned to a truly bleak winter.

However, the Government remains insistent that there is no rationale for extending WFPs to disabled people, arguing that they already receive help with the extra costs associated with their impairment(s) via the system of disability benefits. The ignorance this demonstrates of the well-documented links between

disability and poverty is worrying and suggestive of a Government out of touch with the reality of life for many disabled people.

What is required is for the WFP systems to be extended to encompass disabled people on high-level DLA. The only reasonable alternative would be to entirely overhaul the system of disability benefits to create a situation where the benefits actually do cover all the extra costs associated

with living with impairment.

The UK Government has a legal duty to eliminate fuel poverty amongst vulnerable households by 2010. This is simply not going to happen unless the Government acts now to ensure that disabled people can afford to adequately heat their own homes. Disabled people need to voice their views on this issue and add weight to campaigns currently running such as the National Right to Fuel Campaign and the End Fuel Poverty Coalition. It is definitely worth taking some time out from sunbathing to campaign for the rights of all disabled people to keep warm this winter.

- For more information, see the National Right to Fuel Campaign [www.righttofuel.org.uk](http://www.righttofuel.org.uk)
- There is also a facebook group: End Fuel Poverty Coalition

## → Have your say

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# politics

## Unity, equality, capacity



Disability  
Listen Include Build

A recently formed alliance aims to give disabled people the wherewithal to fight our own battles and campaign for change says **Stephen Lee Hodgkins**

**T**he impact of the recession on the survival prospects of many third sector organisations will be foremost in the minds of many Disabled People's Organisations (DPOs), as they struggle to balance the books and compete for income and contracts to safeguard the futures of their organisations against a worsening economic climate.

But the reality for DPOs, as a distinct sector within the third sector, is that the challenges they face have their roots in problems which pre-date the collapse of the banks and the current economic panic. There are deeper, more fundamental reasons why life at a DPO too often feels like a high wire act.

No other social change movement is so dominated by people without the direct experience of that which they seek to address. We chant "nothing about us, without us", yet we have very limited control and are often left out when it comes to what we have shown we can do well at.



Confronting those issues and working to rekindle a collective DPO power is now the focus of a major three-year Big Lottery funded project, Disability LIB, which has just held its first national conference, "Disabled People's Organisations: A Force for Change".

Disability LIB is an alliance which came together in 2007 to challenge the causes of DPO survival problems.

Disability LIB offers DPOs capacity building advice, support and training. It works on shared experience adapted around what each individual DPO needs.

Our work supports DPOs in the UK to overcome

current issues and build on their previous successes, to be strong, loud, sustained, politically well organised, and a force to be reckoned with in national, regional and local policy and commissioning frameworks.

We also need to have a collective force in order to affect progressive social change. Current issues around welfare reform and the UN convention on the human rights of disabled people are clear examples: whilst we need to understand what these

changes will mean for disabled people and our services, we also need to be in a position to effectively challenge the policy decisions that are being made about us.

DPOs can certainly be more effective together, but there has to be a clear recognition and respect for our diverse differences. Through better communication and more time together listening, recognising and valuing the unique style and contribution we each can bring, no matter our focus, locality and way of doing things, our fight for human rights will be stronger. At this time of financial crisis and political opportunity we must draw on the wide range of business skills and campaigning expertise we have amongst us. This will help us achieve our anti-disablism mission.

• For more, contact [stephen.hodgkins@disabilitylib.org.uk](mailto:stephen.hodgkins@disabilitylib.org.uk)

### → Have your say

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# mediawatch

## Lizzie Lakely: *Emmerdale's* new likely lass

With all eyes in the Wool Pack on a new blind character, **Ivy Broadhead** checks out soap's latest arrival

Something strange is happening in TV-Land. After years of disabled people asking for real, rounded disabled characters played by disabled actors, the execs finally seem to be listening.

We've had a troubled Deaf teenager on *Shameless*, a wheelchair-user flirting her way around *Hollyoaks*, and a schoolteacher with restricted growth on *Eastenders*.

Now *Emmerdale's* getting in on the action with the introduction of Lizzie Lakely (Kitty McGeever), a mouthy middle-aged blind woman who arrives in the village as part of community service.

She turns out to be an old friend of Lisa Dingle's and wastes no time in exploiting her old friendship for the sake of a free dinner, and when she gets chucked out of her accommodation, a bed for the night as well.

Blind she may be, but inspirational she's not. Lizzie cheats, lies and steals her way around the dale, from lying about a lost wallet on the bus to sneaking a sip of other people's pints in the pub; she's not above using her blindness to get what she wants. If people are going to patronise her by excusing her behaviour on



**Five-finger discount:** *Emmerdale's* new Lizzie Lakely (left) isn't above exploiting her blindness

account of her blindness, she's not going to be the one to stop them.

Some might argue that with so few disabled characters on mainstream telly, it's important that those we do see don't reinforce negative stereotypes.

But a choir of angels does little to normalise disability or raise understanding.

Characters in soap operas are caricatures, from the joyless spinster Edna Birch to Eric Pollard, the money-grabbing businessman, and Lizzie the petty criminal is no different.

The reactions of the other characters in the show to Lizzie's blindness seem quite realistic so far, from curiosity and surprise to concern over her ability to manage pouring gravy over her roast dinner or making it to the pub on her own. The latter's certainly not anything she has trouble with.

It will be interesting to see how the character develops

and is involved in future storylines. My hope is that the writers will continue to maintain the balance of not denying her blindness but not fixating on it either.

From what we've seen so far, I reckon she'll fit in pretty well with all the underhand local politics, OAP-romances and child custody battles that seem to keep the rest of the *Emmerdale* residents busy.

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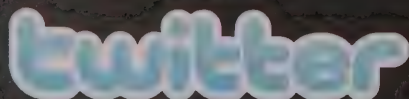
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# disabilityrights

## Ducking the hate crime challenge

**C**ampaigners say that a new plan to help combat the assault and harassment of disabled people in the UK is a step in the right direction but “overdue”, and that they’re weary of the narrow “thematic” approach adopted by the plan’s sponsor, the Equality and Human Rights Commission (EHRC).

The three-tiered plan, part of the report *Promoting the Safety and Security of Disabled People*, aims to support disabled people who are experiencing or are at risk of harassment and abuse and living in fear.

It was unveiled by the EHRC’s chairman Trevor Phillips (photo, right) at the end of April.

However, disability rights campaigner Anne Novis, a trustee of the UK Disabled People’s Council, said that

**“The EHRC should consult more with specialist disability rights groups and individuals when conducting its research”**

the “themed” review was too focussed on working with local authorities and that the research didn’t capture



Activists insist that narrowness at the Equality Commission and its avoidance of the term “hate crime” may lead to blind spots, says **Cathy Reay**

the wide range of problems that disabled people of all backgrounds face.

Mr Phillips agreed that there were gaps in the research but insisted that “this thematic review will be an important platform for further regulatory action.

“We can have the best legislation in the world,” he went on, “but it’s worth nothing if it’s not applied or enforced.

“There’s still a long way to go before public bodies are knowledgeable enough to

meet their legal requirements. Our role is to clarify the statute to public bodies in light of both new and existing laws.”

Abigail Lock, head of advocacy and campaigns at Scope, suggested that the avoidance of the term “hate crime” in the new report and plan was confusing.

Mr Phillips replied: “What we think of as hate crime doesn’t encompass all targeted violence being dealt with in this report. Simply putting it in the hate

crime box would potentially rule out some of the worst of what’s going on.”

When asked by *Disability Now* to put a time frame on being able to provide the right level of support for disabled people who experience or are in fear of experiencing hate crime, Neil Crowther, disability programmes director at the Commission, said: “I don’t think it is possible to put a date on it.

“But our work is designed to communicate to others the urgency to act on this injustice and the consequences of inactions, and we are impatient for change.”

Mr Crowther said that two of the EHRC’s next steps will be reviewing safety and security issues on the reform of social care in England and independent living in Scotland.

In reply to an observation by Ms Novis that the EHRC should consult more with specialist disability rights groups and individuals when conducting its research, Mr Phillips said: “I am keen to highlight the ways in which we can support the involvement of disabled people.

“The way we manage this shouldn’t just be down to bunging a letter to local authorities now and again.”



## worldview

# Home and Away

English people are reserved and stand-offish, so don't expect the same level of assistance from them as you get here in Australia: that was the warning cry as I left Oz for the UK. It's true that Aussies make friends more quickly, and if you're in trouble they're more likely to jump in and pull out all the stops to get you out of it, but they're also very conscious of their personal space and their interactions with strangers can be more tentative.

The English tend not to get involved as much if they think you're about to cry, but as long as emotion isn't involved, I find Australian prejudices are unfounded. Overall, people in England tend to treat people with a disability a bit more like we're part of the community. When I'm out and about, they offer help more seamlessly and with more sophistication than back home.

Aussies are quite vague about giving directions but while England's lovely old winding streets can be a challenge, I usually get the help I need to get where I want. Often, if people don't feel able to explain how to

When Aussie journalist **Lee Kumatat** (*below*) was pondering whether to leave her native Sydney, she didn't question the truth about the different attitudes she was told she might encounter



get somewhere, they'll enlist others to help or even walk along with me. I've had some lovely chats with people as we go in search of a particular destination. I'm not saying this doesn't happen in Australia, but it happens less.

I've only once been asked by a perfect stranger in England how long I've been blind and whether it was the result of an accident or just one of those things. This happens with regular monotony in Australia; quite often it's the opening salvo. Maybe it has to do with Aussies not beating about the bush. Generally speaking though, in England, the subject doesn't seem to come up until much later on in the conversation. Sometimes, I even get to divulge the information before I'm asked, which is almost unheard of at home. If English reserve is to blame for that, then I'm thankful for it.

Steps present a challenge – not for me but for my guide dog, who has a back problem. I try to avoid them where I can but England has lots of them and the lack of lifts and escalators, especially on the rail and tube

CHERYL GABRIEL



networks, astonishes me. As a young country, Australia seems to have tackled this problem pretty well. I do wonder at a Disability Discrimination Act (DDA) that says that people must be given access to the built environment but doesn't make this possible.

And somebody somewhere has done an excellent job at pointing out the "reasonable accommodations" clause in the DDA, because it's bandied about as an excuse much more often here than in Australia. I'm yet to find out who gets to decide the boundaries of reasonable.

Australia's definition seems stricter than England's. For instance, although I wasn't old enough to experience it at first hand, I understand that some of the things that England still considers as "reasonable adjustments" were done away with in Australia 30

**Having to use different phone numbers can feel quite insulting if I'm having a fragile day**

years ago: practices like offering to mind my guide dog while I go to the theatre, in case someone steps on him and breaks his neck, just don't happen in Oz any more.



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**"Australians are very conscious of their personal space ..."**

Another phrase people hide behind in England is "for occupational health and safety reasons". I hear that too often from official-sounding people. It's not that safety is valued less in Australia, but they do seem better at acknowledging that common sense must partner rules and regulations.

While I do feel less isolated here and in some ways more involved in the community, ways of addressing disability and access, especially in recreation, seem less integrated. Having to use different

phone numbers from everyone else if I want to book assistance on a train or make a booking at the theatre can feel quite insulting if I'm having a fragile day.

Another practice that seems rife here and boggles my mind is that of keeping disabled toilets locked in public places. I don't recall ever having to track down a master keyholder in Oz and follow them cross-eyed and cross-legged back to the toilet, so they can open the door for me. I don't understand why this needs to

happen. Isn't it better that some people will use a toilet that they're not entitled to than for others to have to submit to the power of the keyholder for that day?

It's interesting to observe the differences between our two countries. I hope that any decision about which of them to live in won't be decided by any of them. I think it would be a sad indictment, and not of that country but of myself. If it's a competition, for me, it's still level pegging between Australia and England.



## Everybody do the Shannon



The Shannon is a technique of dancing and skateboarding with crutches pioneered by American performance artist, Bill Shannon, who currently stars in a mesmerizing journey through a cityscape in a TV ad campaign for Visa. As is befitting of a performance artist, he takes our ten questions as a chance to consider life, death and transcendence.

### **What's the best thing about being disabled?**

Being alive.

### **What makes you angry?**

I get angry with myself when I fail to live up to my ideals of how to live and be responsible.

### **What's the funniest thing anyone's ever said to you about your impairment?**

I skated past a father and son in Brooklyn. My friend and DJing partner was on a bike behind me and overheard the son saying "Wow!" and the dad saying: "That is one lazy skater!"

### **If you were Prime Minister what one thing would you do to improve things for disabled people?**

Switch the military budget with the education budget.

### **What's the one thing that could be invented to make your life as a disabled person better?**

A limitless renewable energy source that is environmentally beneficial to plant and animal life around the planet.

### **What do you most like about performing?**

Transcendence: Escaping my internal-conversation and reaching a higher state of consciousness where the body becomes transparent and beyond the directive of thought.

### **And what do you not like about it?**

Travel. I have to explain my unique situation to others in passing, or deal with their power issues, so from the car park to the plane seat it's one ego after another to contend with.

### **Who's your favourite disabled person ever?**

Superman: the irony of what happened to Christopher Reeves makes him one of the real icons of disability versus ability, fiction versus reality, who we project as our ideal self versus who we really are.

### **Do you have any special or hidden talent?**

I know what my hidden talent is and I am hiding it.

### **If you didn't have your impairment, which other one would you like to have for a day?**

Death.

### **How would you sum yourself up in ten words or less?**

That guy just threw a flaming bag of crap on my porch.

### **→ Who do you think is One to Watch?**

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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Having twice flirted with TV stardom, **Sunil Peck** finds Julie Fernandez wondering why she's recognised in the street but not as a campaigner by disabled people in her own community



# Fernandez:

## In and out of *The Office*





**“I've got a Jewish East End gangster father, an Austrian Catholic mother and half of my family in Austria were members of the Nazi party. I've travelled around the world, worked in the media industry, lived in LA working for CBS television and fought for the rights of disabled people”**

KYLIE GARLICK

Julie Fernandez is best known for appearing in the TV sitcom *The Office*. But she'd never dreamt about a part in a classic series. In fact, she had no ambition to act at all and hoped to go to polytechnic to study German and Business Studies. She applied to five polytechnics who rejected her saying that their buildings were not accessible to wheelchair

users. She tried instead applying for a course in hotel management but was told that she could not do that because she would be unable to handle silver service. After 30 or 40 rejections, she had no idea what her future held. But then staff at her school received a phone call from the BBC out of the blue.

“They asked if there was anyone

who could play Vanessa Lockhead in a soap they were making called *Eldorado*. I had always done drama at school, my name was put forward, I went for the audition and got the job.”

That was in 1992. It would be another ten years before Julie appeared in *The Office* as Brenda. She says that *The Office* has been the “best experience” in her 16 year media career, but she rarely watches the DVD now.

“My husband Andrew does, he loves it. He quotes it at me and he gets annoyed because I don't know what he's quoting. It's a script! I learn it, I say it, and then I forget it.”

There has been some TV and radio work since, but how disappointed is she that *The Office* did not lead to more high profile roles?

“It has disappointed me for many years before that. *Eldorado* had nine to ten million viewers per episode three days a week and my character was one of the main characters in the show.”

The episodes of *The Office* she appeared in were produced by Ash Atalla who is disabled and she says that without more disabled producers, agents, writers and casting directors, disabled characters will predominantly play roles as “brave individuals who climb mountains, people who overcome their disabilities or baddies with false eyes and artificial limbs who want to take over the world.”

Julie is not fussy about the kind of roles she plays in the future, goodie or baddie, newspaper editor or even a mother and she is not fussy about the genre either – as long as the role challenges her versatility as an actor and is character-led rather than being defined by her disability.

The couple have no children yet, but are excited about the prospect of becoming foster parents.

They've had long conversations about ➔



having their own baby but Andrew had concerns about the risk of Julie ending up with lots of broken bones as a result of spending months lying in bed.

Although Julie has opted to become a foster parent, she respects other disabled people who choose to have their own children.

"If I have my own child, it will have a 50/50 chance of having brittle bone disease. As wonderful a life as I have had, I've had 70 operations and 100 fractures which is an awful lot of pain and difficulty. It is not easy to live with and I don't wish to give that to another child."

Once they have completed a training course, the couple will be in a position to provide respite care for a disabled child. Julie has an added incentive to offer this kind of service. She says that her own family would have benefitted from it which would have enabled them to spend time together free of the strain on their lives caused by her condition.

"A lot of the attention was on me because of all of the fractures and spending pretty much most of my first 12 years in Great Ormond Street hospital. My brother must have found it very difficult growing up."

Eventually, Julie intends to devote more time to fostering which could involve caring for non-disabled children too.

It might come as a surprise to some that someone who champions equality for disabled children also thinks that special schools can have a place in the education of disabled children.

Julie says that whether a disabled pupil attends a mainstream or a special school should be determined by his or her disability and support needs.

"As a person with brittle bone disease, going to a mainstream school would not have been a sensible option for me because it would have been too



PHOTO SUPPLIED COURTESY OF MOTABILITY

dangerous. Schools that specialise in children with disabilities can cater for children in a way that a mainstream school could never do because they don't have the funding."

Julie was a pupil at Treloar school in Hampshire which had its own driving instructor with adapted cars, hospital and physical and occupational therapists which meant that her physical needs could be integrated into her everyday schooling.

### **She had no ambition to act at all and hoped to go to polytechnic to study German and Business Studies**

While things are quiet on the media front, Julie has been devoting time to campaigning. We meet a few days after Julie co-hosted an event promoting voluntary work for disabled people.

Another cause close to her heart is the plight of mothers of children with undiagnosed conditions, brittle bone disease for instance, who can face accusations of child abuse from the police and social services after taking their children to A&E with fractures and broken bones.

"It happened to my mum and it's

happened to the parents of many of my friends. It's rife in the UK not just with brittle bone disease, but with many disabilities."

She has her own charity too, the Disability Foundation, which is staffed by disabled people and offers the kind of complementary therapies which have helped her recover from surgery. Therapies like massages, reflexology, acupuncture and shiatsu.

She also works with the campaigner Phil Friend running equality and diversity workshops.

Phil says that her acting skills have proved to be an effective tool for raising awareness of disability issues in businesses.

"Not only is she an actress, but she is very passionate about equality and disability rights. Sometimes she can be very forthright and other times she can be very subtle. It just depends on the audience. It's a different form of campaigning."

But despite her campaigning for greater equality and her achievements as an actor, there is something nagging away at the back of Julie's mind which makes her think that she has said or done something to offend the disability community. She says that Mary Wilkinson's book on the most influential disabled people has been



an excellent read. But she is miffed that she was not considered worthy of inclusion and that she was not even approached to contribute to the chapters on people who she considers to be her colleagues and peers.

"It's a bit disappointing but I'm not bitter. My career has been very much acting and presenting, but I have been quite high profile and worked very hard over the years to support and fight for equal rights for people with disabilities in lots of different ways. It's a bit disappointing because it makes me think where am I going wrong that I'm not included in this list of people who I have worked so often and so hard with?"

So what does the future hold for Julie? Going by her career trajectory with its gap of ten years between

*Eldorado* and *The Office*, it will be 2012 before she lands another big role on TV.

But she has co-written a comedy sketch show aimed at disabled and non-disabled people which is based on the real life experiences of disabled people which she is pitching to TV executives.

She is keen to write about her experiences of seeing ghosts and she has also spent the last year trying to secure a publishing deal for her autobiography. Whatever the future has in store, Julie says that her experiences so far would make fascinating material for a book.

"I've got a Jewish East End gangster father, an Austrian Catholic mother and half of my family in Austria were members of the Nazi party. Some of them were pro-Nazi and some of them were involved in helping people to

escape. I've travelled around the world, worked in the media industry, lived in LA working for CBS television and fought for the rights of disabled people."

Julie never knew the Kray twins, but her father did. She did grow up with other gangsters, or "bad people" as she describes them, but her perspective of them is very different to the brutal image most of us are familiar with.

"I used to have these plasters that went from my toes up to my waist with an area cut out to go to the toilet. Often, if my father and brother weren't at home and I needed to go to the loo and my mother couldn't lift me, this gentleman friend of mine, who is a gangster, would take me to the toilet. That's how I grew up knowing him. He helped me, I don't know him any differently. What can I say?" ■

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# T4: Hitler's holocaust rehearsal

As *Resistance*, a new touring installation, prepares to hit the road, its creators and performers, along with historians and activists, look back with **Kelly Mullan** at T4, the Nazi killing programme on which it reflects, and asks what lessons can be learned today



A montage of photos from the walls of the killing centre at Bernburg. Ludiya, pictured second from right, bottom row, was a teenager who fell from a ladder, resulting in neurological impairment, epilepsy, some learning difficulties, and a walking impairment. Her family loved her. She was registered at a hospital and at 16 was sterilised. A year later, she was removed from her family and killed

In 1939, Hitler authorised Aktion-T4, a programme of mass-murder targeting disabled people. T4, combined with unstructured so-called "wild euthanasia", killed more than a quarter-of-a-million disabled people, yet this history is largely

forgotten. Indeed, thanks to the light-entertainment phenomenon of the same name, the mention of T4 is more likely to evoke images of Miquita Oliver on the beach than disturbing scenes of grey "death buses" transporting disabled people to killing centres.

Of this "death bus"-shaped hole in history, Dr David Bolt of the Centre for Disability Research at Lancaster University says: "I wouldn't say that little is known about T4, rather that the knowledge is too frequently ignored and too infrequently disseminated."







Sophie Weaver reflects on her visit to a killing centre in *Conversations*

Why? Disturbingly, because the lives of disabled people are sometimes deemed less valid, so the twisted logic is that the lack of representation makes perfect sense, as though there would be little interest in any such history."

Artist Liz Crow has responded to this historical phenomenon by creating a dual-screen installation that will tour the UK this autumn. At the core of the installation are two films. One, *Resistance*, is the story of Elise, a patient who sweeps her way out of an institution to escape as a grey bus pulls up. The other, *Conversations*, is a "making-of" documentary where actors discuss the impact the project has had on them. As director Crow

## “Disabled people were taken from holding centres to killing centres and killed on the same day”

says: "All of the disabled people involved felt it personally. It's our community's history."

Claudio Ahlers, who composed the music for *Resistance*, says: "I'm German and I've learnt much about the atrocities that were committed during the Nazi regime; yet this was the first time that the systematic killing of people with disabilities was brought to my attention."

Eva Fielding-Jackson is the daughter of two profoundly Deaf Holocaust survivors. She says: "I knew about the Holocaust since the day I was born (well, from the day I could understand things), but I only knew about T4 from a conference I attended in Washington in 1998. I knew about the euthanasia and the mercy killings but not that it was originated by the T4 programme. I was well informed about the Holocaust, so if I didn't know then how many others still don't know?"

Asked why so little is known about T4, Crow says: "Museums ask: 'Where's the first-hand testimony? We'll be interested when we see that.' But this was a different type of holocaust. Jewish people were taken to concentration camps and some were able to survive there and eventually give evidence, whereas disabled people were taken from holding centres to killing centres and killed on the same day."

Medical confidentiality is another barrier to gathering evidence. "I find this absolutely ironic and it adds to the horror," says Crow. "The names of prisoners persecuted in concentration camps are available, but because disabled people were in the medical system they are subject to confidentiality. Relatives need to consent to releasing names but many won't because of the stigma, particularly of the psychiatric system."

"Even our visits to the killing centres yielded scant information on individual stories. There were about half a dozen case studies available because the

relatives of those people came forward and they said they wanted them to be remembered."

Crow discovered the story of Elise in a book called *By Trust Betrayed* by Hugh Gregory Gallagher. "What struck me were the stories of resistance. Resistance doesn't have to mean stashing guns in a forest. You can resist by saying no."

It was a seemingly small act of resistance taken by disabled people in the town of Absberg that eventually ended T4. In Absberg the disabled people from the holding institution socialised with the local townsfolk, so on the eve of the day they knew that they were being sent to the killing centre they knocked on every door to say goodbye. They didn't save themselves, but the people of Absberg were so outraged that they protested, leading to the intervention of Bishop Von Galen and the cancellation of T4. This was the end of structured killings but "wild euthanasia" continued until three weeks after the end of the war.

At the Nuremberg trials, very few medical staff were prosecuted and most were allowed to continue practising until retirement or death. Due to the prevailing values of the age, the authorities at Nuremberg could empathise with the notion of mercy killing. T4 was carried out against an international background of eugenics policies, which is why Crow says, "this is not about Germany, this is internationally relevant and relevant today."

"In 1920 a research paper set out the mechanics of T4. So it was pre-Hitler, under the guise of mercy



A still from *Resistance*: Lou Birks plays Elise





**Smoke from the killing centre at Bernburg rises above the town**

killings, but it was really on economic grounds. Sums were done on how much it would cost to feed someone with X impairment on a basic diet and how that would accrue over a lifetime.

"T4 was an extreme event, but if you look at the values that underpin it, they feel very familiar. The installation will connect themes and link into the campaigns that *Disability Now* runs. I hesitate to say this, as it's controversial, but the values that allow abuse of parking bays are on the same spectrum (albeit very far down the other end) as the values of people who commit hate crimes. What drives this project is how we can learn and how we can change. Storytelling is a good way to get under people's defences."

Disability historian Irina Metzler says: "The uncomfortable truth is that the

debate on who are valid and non-valid human beings was not just forced to its extreme level by the Nazis. Eugenics was also practised by a number of so-called democratic countries, notably Sweden and Switzerland, with programmes of enforced sterilisation for people deemed 'deficient' right up until the 1960s.

"More people than just a handful of specialist scholars need to know that disabled people were just as systematically persecuted by the Nazis. The need to know is made all the greater by current developments in

the medical and biological sciences, specially in genetics, which re-open the possibility of scientific and popular debate about what is and what is not deemed a 'valid' human being.

"Genetic science can aid prognostic medicine and influence procreative medicine; genetic screening, if carried to its logical extreme, means that parental selection will reject any embryo with so-called defects; and a renewed promotion of eugenics is not unlikely. This timely installation will help to focus popular attention on the fact that in any such eugenic programmes (whether murderous or simply 'preventative') there are real, actual people, with individual lives, characters and stories, who are caught up in what is presented purely as science."

Disabled activist Linda Burnip says: ➔

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"Sadly, there are a lot of things going on today which in relation to disability are reminiscent of how the Holocaust began in Nazi Germany, not least the ghettoisation of disabled people in residential care, the promotion of social attitudes through adverts on buses about benefit fraud, the changes to Employment and Support Allowance etc which give the impression of disabled people as a burden to society and nothing more than a lot of scroungers. Disabled people seem to be being divided into two groups by Department for Work and Pensions legislation and society generally: there are 'acceptable' disabled people who are able to work and support themselves and aren't a financial burden on the state and then there are 'the others'. I think that *Resistance*

**T4 was an extreme event, but if you look at the values that underpin it, they feel very familiar. The installation will connect themes and link into the campaigns that *Disability Now* runs**

should be shown as a warning of how easily the situation could worsen if nothing is done to stop it."

Commenting on the installation Richard Rieser, the director of Disability Equality in Education, says *Resistance* is relevant now as "the scapegoating of disabled people grew out of an economic crisis which is similar to the one we are now entering."

Bolt adds: "The fact that millions of Jewish people were systematically murdered in Nazi Germany has brought shame on humanity for eternity, but this is only worsened if we forget that thousands of disabled people were subject to the same inhumanity. Projects such as *Resistance* will surely help to stop this from happening."

Rather than depressingly focusing on the continuing plight of disabled people, *Resistance* looks at the continuing fight for disability rights and uses storytelling to encourage debate on how to learn from the past.

*Resistance* will be on tour from September. ■

• Liz Crow welcomes any venues interested in hosting the installation to contact Roaring Girl Productions. [www.roaring-girl.com](http://www.roaring-girl.com)

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Renault Kangoo 1.2 Petrol	RX07 OCP	3 Seats, Air Con	Mt Blue	5,725	8,295
Renault Kangoo 1.5 Diesel	PN57 HVK	3 Seats, Ramp A/Con	Silver	5000	8,995
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# yourviews

## The cycle of change



I liked Alan Sutherland's article about cycling for disabled people (*Disability Now*, April 2009). May I add that a new forum has started up, to get disabled people's voices heard: the London Disability Cycling Forum (LDCF), a network for disabled cyclists and providers of cycling services such as cycle training providers and groups that run cycle sessions.

The voices of Deaf and disabled cyclists, cyclists with mental health issues and cyclists with learning

disabilities are still too rarely represented. That's why we're working to ensure that anyone with an interest in cycling includes disabled cyclists in all aspects of their work.

In addition to cyclists who are disabled, our members include organisations such as the RNIB, the London Sports Forum for Disabled People, the London Cycling Campaign and Transport for London (TfL). We're also trying to influence TfL to include cycling in its next Disability Equality Scheme,

after it was excluded from TfL's 2006-2009 scheme.

For many of us, cycling can change lives: it can be a safe way to stay fit, solve the problem of panic attacks in the tube, and make working a possibility. It can also be the easiest way to get around when walking any distance isn't an option.

Some people can find out about cycling options quite easily and can afford their own kit, but others can't, so we run "try it out" projects to give disabled people opportunities to build confidence and stamina at various off-street locations.

In my own case, I'm not likely to take up commuter cycling myself; keeping up with my son in the park and sharing in his fun wouldn't have been possible without the hand-cycling attachment to my wheelchair. I've also realised that hand-cycling provides me with the only non-damaging form of fitness exercise I can find, and what better fun it is than sweating at the gym!

You can find more about the LDCF at <http://www.wheelsforwellbeing.org.uk/wfw/index.php/ldcf>  
**Isabelle Clement**  
**Chair, Wheels for Wellbeing**

## Paying the price of change?

I was disappointed to note that you haven't mentioned the fact that all disabled people on Income Support or severe disability allowance will shortly be robbed of a week's money when the system changes to fortnightly in arrears instead of seven days in arrears. To rob disabled people in this climate is diabolical and I hope this Government will hang its head in shame.

**Bob Brown, by email**

## Editor's note

We made several requests to the Department for Work and Pensions for a response to this letter and allegation. At the time of going to press they had not given us one. Mr Brown's query is clearly a matter of concern to us and our readers. We'll keep up our efforts to find and tell the full story.

## View from the forecourt

Motability would like to respond to comments made by Frances Leckie in "Your Views" (*Disability Now*, May 2009). We maintain a range of highly affordable motoring options for all drivers. The scheme has indeed seen exceptional



growth in recent years, in tandem with record levels of customer satisfaction, and this is across the range, on all types of cars.

For more than four years we have consistently provided more than 200 cars at no advance payment, including family cars such as the Ford Focus and Vauxhall Astra, plus a range of automatics.

Ms Leckie mentions the VW Touran. For clarification, both the 1.9 diesel and 1.6 petrol models are currently available at £799 advance payment.

As well as standard cars, we aim to meet the needs of disabled drivers who require adaptations, with a range of driving controls, including hand controls, at no extra charge. Last year more than 12,000 customers ordered cars with adaptations through the scheme.

We also supply a range of wheelchair-accessible vehicles at less than £500 advance payment and now have more than 10,000 customers who have therefore been able to access the mobility that a WAV provides at the most affordable levels.

Clearly, Motability is not immune from the economic climate and car prices have risen from many suppliers in line with reduced levels of production and the fall in value of the pound against the Euro. However, we are

committed to providing a full choice of affordable cars for all our customers for the long term.

**Delia Ray**  
Head of Marketing,  
Motability

## The 'the' word

I agree with Bonnie Salmon, who wrote in the May issue of *Disability Now* (Letters: "Saying 'the disabled' isn't acceptable") that she objects to being referred to as "the disabled". I find it offensive that national and local government, and press, TV and radio use the term both verbally and in writing. We are people, and the difference between "the disabled" and "disabled people" is just one syllable and three characters. I find it disgusting that they begrudge us even that!

**Sally Dixon, by email**

## Problem? What problem?

I read with interest about the person who wants the local council to have its own toilet-key system ("Ask The Experts", *Disability Now*, May 2009) and would ask where disabled visitors would go to collect the key when they go to a new area? And if other councils followed suit, surely this would create a system whereby, wherever you went, you'd need to

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Figure 20 — Unlatching Battery

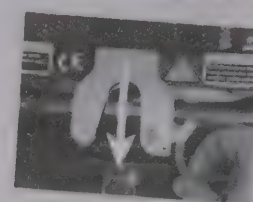


Figure 21 — Releasing Battery

Figure 22

You can remove the seat from the vehicle either folded or unfolded. To remove the seat, release the red latch handle at the right rear of the vehicle, and lift the seat away from the vehicle. (Figure 23) To remove the seat in its unfolded position, release the latch handle at the front of the seat upward; slide the front legs rearward out of the leg sockets. The latch handle will be visible, lightweight seat when it is not attached to the vehicle. If you sit in the seat when it is not attached to the vehicle, it will place it on a firm, level surface. (Figure 24)

# Manual labour

Why is it impossible to get a workshop manual for a mobility scooter? I want to be able to repair my scooter myself or at least have an idea of what's wrong with it, but I can't get the information. I can get manuals for other cars and bikes but not mobility scooters. Discrimination or what?

**Janet Fleming, by email**

## Editor's note

We checked online and found downloadable manuals for Invacare, Pride, Shoprider, Sunrise and Electric Mobility scooters on the website of DiscountScooters.co.uk. Click on Download Manuals on the sidebar menu on the left, under the heading "More Information".

apply for keys, and then you'd have more keys and more extra weight to carry, as you'd often or not forget which key belongs to which set of toilets. So I say: leave

well alone and keep with the RADAR key system. It works for all.

**Charles Ricketts (a very appreciative RADAR key user), by email**

## → Have your say

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## That continental touch

As we choose the people to represent us in the EU Parliament, **Andy Rickell** reflects on how Europe has led the way in establishing rights for disabled people

**T**urnout in European elections is traditionally low and the level of interest in what goes on in Strasbourg and Brussels even lower. However the EU is useful in advancing disabled people's rights in the UK.

**“The EU law may correct some of the DDA's weaknesses, like the ludicrous definition of disability”**

The major change recently has been the EU Employment Directive. Sounds boring, but this was the legislation passed by the EU which required the UK to take account of discrimination in employment on grounds of age, religion and sexual orientation, as well as race, gender and disability. The UK chose to create the Equality and Human Rights Commission. Whilst disabled people lost our Disability Rights Commission, we gained

a recognition that disability had a rightful place alongside all other equality and human rights issues. Soon we will also get a new single equalities law which will again recognise disability.

Recently a further key step was taken. Years ago when I was Chief Executive of BCODP, then Britain's leading organisation of disabled people, the European Disability Forum was touting the idea of a specific EU disability directive – basically a Disability Discrimination Act (DDA) for the whole of the EU, which would trump the UK's DDA and help to deal with its weaknesses. As BCODP was struggling to get progress on improving the DDA as we wanted, this was a good opportunity to bypass the Westminster government. Some Members of the European Parliament supported this law, but that itself was not enough.

Then the European Disability Forum

orchestrated a mass European-wide petition in support of such a law. The EU rules are such that if one million people petition for something, they have to look at it. I and many other activists and ordinary people signed this petition, and the target was achieved.

At the beginning of April, the European Parliament voted on introducing this new EU

**“We gained a recognition that disability had a rightful place alongside all other equality and human rights issues”**

law which would cover discrimination relating to access to goods and services, and it was passed. Next it must be

agreed by the Council of Ministers before it becomes EU law and it will then apply in the UK.

This EU law may correct some of the DDA's weaknesses, like the ludicrous definition of disability, and the difficulty of enforcing your rights under the goods and services section.

The EU law would use the same definition for disability as the UN Convention – based on the social model – which concentrates on acts of discrimination and not a person's impairment. This would be good. Indeed, already the UK Government has been thinking about how this will affect the definition in the UK's single equality legislation.

The bottom line is that the EU is useful in pushing the equality and rights agenda for disabled people in the UK.

### → Have your say

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- phone us 020 7619 7323



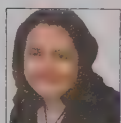
# asktheexperts

you ask, they answer

## QUESTIONS AND ANSWERS

**Q** I receive the lower rate of Disability Living Allowance (DLA). I'm agoraphobic, so can't seek help in person at an Advice Centre or similar. I need to know if I'm entitled to any other help than DLA, LHA, council tax benefit and Income Support. My Income Support is under appeal as I could not attend a medical examination as I can't travel.

Name supplied, by email



**Selina Mills  
and her team  
at CAB  
respond:**

It seems that you're getting all the benefits you're entitled to, based on your circumstances. There may be other types of help and support available from social services or the NHS for people with agoraphobia in your area. Were your DLA award increased so you got the middle rate care

component, you might then get an additional amount of Income Support as you may qualify for the severe disability premium. There are, however, risks involved with asking for your DLA award to be increased, as the award could be reduced instead of increased. You should therefore try to get advice about the chances of success before asking for the award to be looked at again. If you don't win your Income Support appeal, you may have to make a new claim for Employment and Support Allowance and may have a gap in your benefit payments. So we'd really encourage you to get advice from your local Citizen's Advice Bureau or other advice agency for help and support with the appeal and to advise you on your overall benefit entitlement. Some advice centres are able to give advice over the phone or make home visits.



## THE EXPERTS

We have experts who can answer questions in many areas that matter to us.

**Sexual & Personal issues:** **Simon Parritt**, a counselling psychologist who has studied psychosexual therapy, was the only disabled director of the

Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD).

**Legal Matters:**

**Douglas Joy**, senior solicitor at the Disability Law Service, and his colleagues give advice on

disability and the law.

**Benefits and Debt issues:** The **Citizens Advice Bureau** puts its expertise at our disposal to help you.

**Technology and Internet:** **Léonie Watson** from digital consultancy Nomensa is here to get you

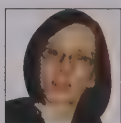
connected and keep you up and running.

**Specialist or Adaptive Equipment:** **John Mandrak**, for nearly 25 years a disability journalist and consultant, gives advice on the Disabled Living Foundation's helpline.



More advice and contact details for your local CAB can be found at [www.adviceguide.org.uk](http://www.adviceguide.org.uk). You can find the phone number for your local CAB and other advice agencies in the phone book. Aside from benefits and finance issues, it may also be well worth your while seeking advice and/or support from local health professionals in respect of other aspects of your agoraphobia.

**Q** I'm 64 years old, I'm very small, and I desperately need a new power wheelchair. I've had lots of people trying to get me one, but with no success. The only person who could help me wanted £8,000 for a bespoke one and as I'm self-funded I couldn't afford this and, indeed, can't see why I should. I can't be the only small person who uses a wheelchair. Do you know anyone who makes them?  
**Judy Smart MA, by email**



**Agnes Fletcher offers these suggestions:**

Your query is really in two parts: (a) you need to access a small chair, and (b) you're facing potentially large costs for getting one. Your first port of call, if you haven't already tried it, should be your local NHS wheelchair service. You could also talk to your occupational therapist (if you don't have one, you could ask for one via your local social services) or a physiotherapist. This may help you find a suitable supplier, to avoid the bespoke route, and may also provide an up-to-date assessment of any further financial support that you may be eligible for. It could be, for example, that you access other improvements, such as a Disabled Facilities Grant to make adaptations to your home. An occupational therapist can be the key to accessing such funding and support. Do you receive the higher rate

mobility component of DLA or the War Pensioners Mobility Supplement? If so, the Government's Motability scheme could help you get a new powered wheelchair. Around 470,000 disabled people pay their allowances to the Motability Scheme to meet the cost of having a car, powered wheelchair or scooter, through contract hire or hire purchase plans. You have to give up that part of your DLA but Motability can help you find the right chair and also deal with insurance, extended warranty, 24-hour breakdown recovery service, servicing and repairs. Of course, it's likely that you're already using your DLA to pay for other disability-related costs but you might want to consider whether you'd be better off making this arrangement – and

regularly getting a new chair – or making a one-off payment to buy a chair on your own. Another possible route, if it seems you really have to go it alone on both funding and finding the right chair, could be asking the advice of Whizz-Kidz, a charity that specialises in chairs for disabled children. They have contacts with commercial companies that cater for smaller people. While *Disability Now* can't recommend particular companies, Whizz-Kidz does list some of the companies it works with around the country: [www.whizz-kidz.org.uk/gethelp/getequpment/equipmentsuppliers](http://www.whizz-kidz.org.uk/gethelp/getequpment/equipmentsuppliers).  
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**→ If you have a question for our panel**

- phone us 020 7619 7323
- write to us *Disability Now*, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)

**Travel:** Andy Wright is managing director of Accessible Travel, a specialist tour operator providing holidays for people with mobility impairments, and has huge experience in the travel trade.

**Money management:** David Clarke has spent 14 years in banking and has worked for three leading financial service providers. He is now a senior partner with Clydesdale Bank and his wealth of experience is all yours.

**Access & the Environment:** Agnes Fletcher is a disability trainer and consultant who can find solutions to access problems.  
**Property:** Kate Sheehan is an independent occupational therapist with 20 years' experience and a

passionate interest in housing solutions for disabled people.

**Motoring & Transport:** Helen Smith of Mobilise steps outside her *Disability Now* column to answer your questions on car matters.



# pete'splace

## Prophecy profits



ASDA's decision to stock "disability aids" is nothing more than hard-nosed economic reality, says **Peter White**

**A**SDA was obviously feeling pretty pleased with itself when it recently announced its new range of "living aids" – that's the commercially acceptable term for all the gadgets that allow disabled people to do what other folk do without gadgets: get lids off jars, walk down the road, go to the loo.

"It will take the stigma out of disability," ASDA purred, along with some of the

other stores doing the same thing. An interesting point, this, since you immediately start thinking: "So who put the stigma into disability in the first place?"

After all, most of these items – wheelchairs, stuff to help you grip, urine bottles, canes to support you when you walk – have not just been invented, as far as I'm aware. They've been on the market for ages and could have been sold at any time

in the past hundred years.

The fact is that two trends are at work here. First, it's certainly easier to talk about disability now that the law has made commercial bodies think about their responsibility to disabled customers.

But more important is the fact that the demographic time bomb, talked about for so long, has finally gone off.

It has finally dawned on the stores that the place where the real money resides is among the over-60s and that although they'll want, like everyone else, decent clothes, furniture and

holidays, they'll also want the practical things that accompany the disabilities of age; and that, given the solidarity that goes with numbers, they'll increasingly not feel stigmatised by wanting to buy them.

**At last what we're seeing is the development of a potentially life-altering phenomenon: a change in attitude**

People will also feel less and less that they need tailored advice on what to choose. After all, no one would suggest you should drag in your literary adviser when buying a book.

At last what we're seeing is the development of a potentially life-altering phenomenon – a change in attitude; but a change of attitude not brought about because people have got "nicer" or more instinctively liberal but the reverse: that among a very substantial section of the population, strong in numbers and rather good at getting together, disability will be the norm.

The irony that magazines and programmes for disabled people have known for some time but never dared utter is that more disabled people is a cloud with a silver lining!





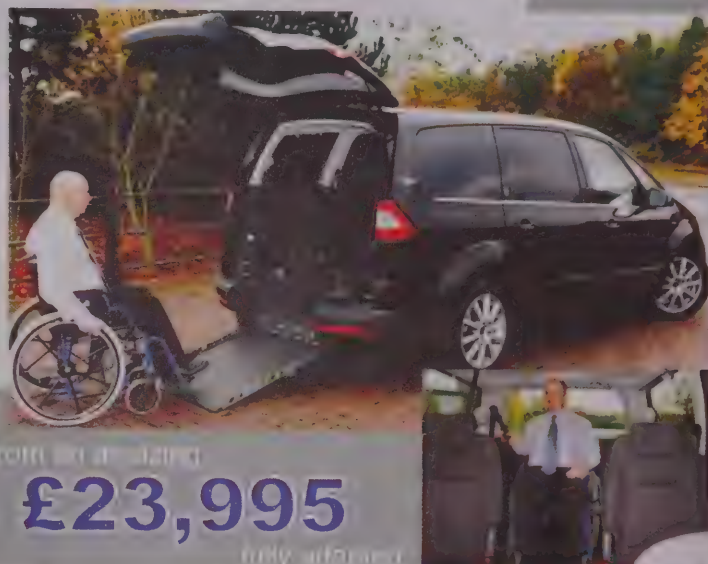
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# guestcolumn

## Work and the inclusion illusion



Since her graduation in 2005, **Lisa Davies** has lost none of her drive to find a job, but is she headed for a brick wall



**L**et's get the boring bit out of the way first... I have cerebral palsy and use both manual and electric wheelchairs to get around. I am that very unrare thing known as a disabled graduate. Since leaving university in 2005, I have filled in over 60 job applications. I can handle the idea that I am not the perfect candidate for every post, but during my quest for that elusive life goal of steady employment, I have heard every excuse from

"sorry love we don't employ spastics" to "we can't afford to employ you". One REALLY NICE GENTLEMAN took one look at me and refused to proceed with the interview, all in full view of the other candidates, one of whom was even kind enough to make sure the door didn't hit me in the ass on the way out. I have even allowed myself to be carried up two flights of hotel stairs in pursuit of a job, batteries and all; luckily for the bellboys I'd only had a light breakfast! So much for

**During my quest for that elusive life goal of steady employment, I have heard every excuse from 'sorry love we don't employ spastics' to 'we can't afford to employ you'**

access requirements. I'd even ticked the little box declaring my disability in advance. I have sent out multiple covering letters in which I am open about my condition. I am considering changing the phrasing from cerebral palsy to wheelchair user, or mobility impaired on account of the success I have had, namely none.

And it's no fun going up as a guinea pig for management trainees to practise their interviewing skills on. The interviews are obviously mock. They

don't even bother pretending to take notes. Bit of a giveaway that.

I have had numerous experiences with employment agencies specifically targeted at those with disabilities, and whilst the few that exist are well meaning I have found them to be ineffective, and I am not alone in this view. Statistically I'm more likely to get an interview when my disability is not disclosed in advance... sad but in my experience true. In reality, though not required by law, this is a risky ill-advised strategy, which leads to considerable stress. It is, however, becoming an increasingly necessary one when confronted with the ignorant attitudes of perspective employers. What use is the DDA and Equal Opportunities legislation when you are viewed as a problem rather than a solution? Do you think if I had mentioned the Social Model of Disability it would have aided my chances of success? It took time to change the law which, although better, is still not fit for purpose. It will take even longer to change the attitudes of individuals.

### → Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)
- phone us 020 7619 7323



# upclose&personal

## Happy in the parent trap

Parent of two **Amie Slavin** thinks she might get feisty when people draw the wrong conclusions about who's looking after whom

**B**eing possessed of what might be politely described as a distinctive sense of humour, I quite often find myself cheerfully declaring that I only had kids in order to get the household staff I can't afford, remembering too late that this is, regrettably, precisely the assumption many people make about disabled parents. Children cast (or forced) into the role of carer, given too much responsibility, and denied childish life far too early.

I have been wondering, since before my first daughter was born, what I might say or do to the first well-meaning person to syrup at her: "And do you take good care of Mummy then?"

She is three-and-a-half now, and whilst I remain alert for well-meaning strangers casually pressuring her into a caring role, I must admit that the question of where the transition from child to helper takes place is a more complex one than I expected.

I am adamant that it is entirely inappropriate to suggest, even in the mildest terms, that my elder



**I have been wondering, since before my first daughter was born, what I might say or do to the first well-meaning person to syrup at her: "And do you take good care of Mummy then?"**

daughter Sophia should be in any way responsible for helping me. It is true, however, that as she demonstrates joy in feeling useful, I do engage her in minor assisting tasks, thus prompting further exploration of the issue.

For example, this morning, when my younger daughter Jihana was experimenting with eating – and thoroughly destroying a slice of bread

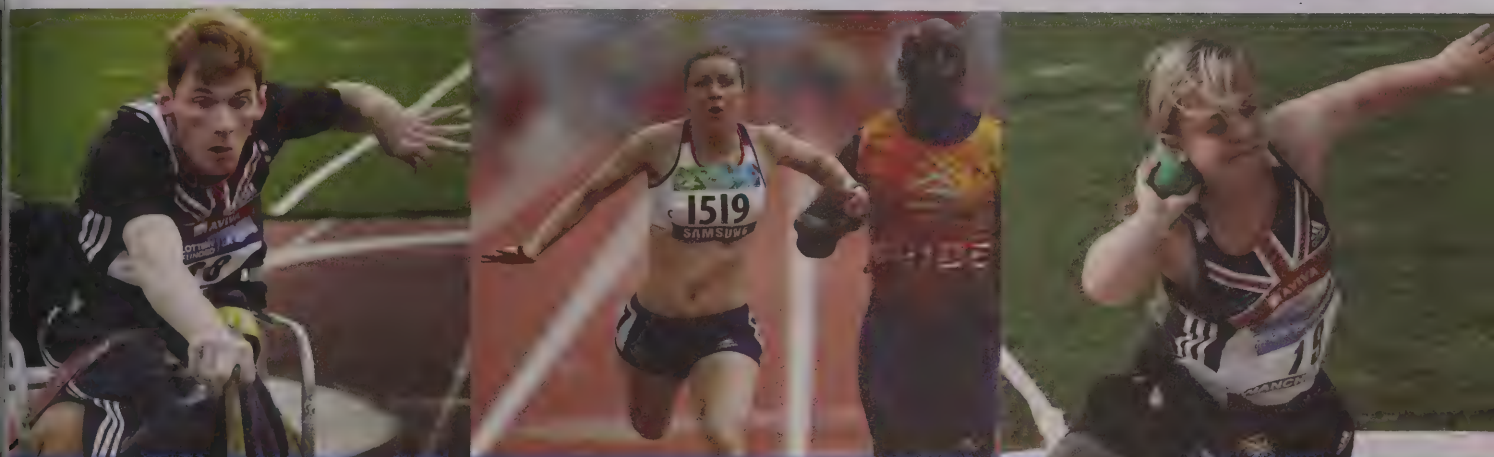
and butter, I asked her sister to help me gather up the stray morsels, as they rained onto the kitchen floor. Was this taking advantage of her excellent eyesight, or was it simply allowing her to join in?

Likewise, when Sophia and I run the gauntlet of her nursery school's main foyer, thronged with miniature people, I try to avoid using my white cane more than is necessary, for fear of taking out tiny knees. As we proceed, hand in hand, I do pay attention to her body language, to assist in piloting us safely to her classroom. This amounts to nothing more than noticing her grip tightening as we approach obstacles, but it wouldn't happen if I wasn't blind.

My own view is that it helps kids to build self-esteem and confidence if they are allowed to take responsibility for small tasks. I don't, however, expect my daughter's help for my own sake and, most importantly, I never allow her to feel I am relying on her.

When she's big enough for real responsibility, I'll get her a pet. Until then, she can care devotedly for her teddies. I'm holding out for that far-off day when she passes her driving test.





# your chance for glory

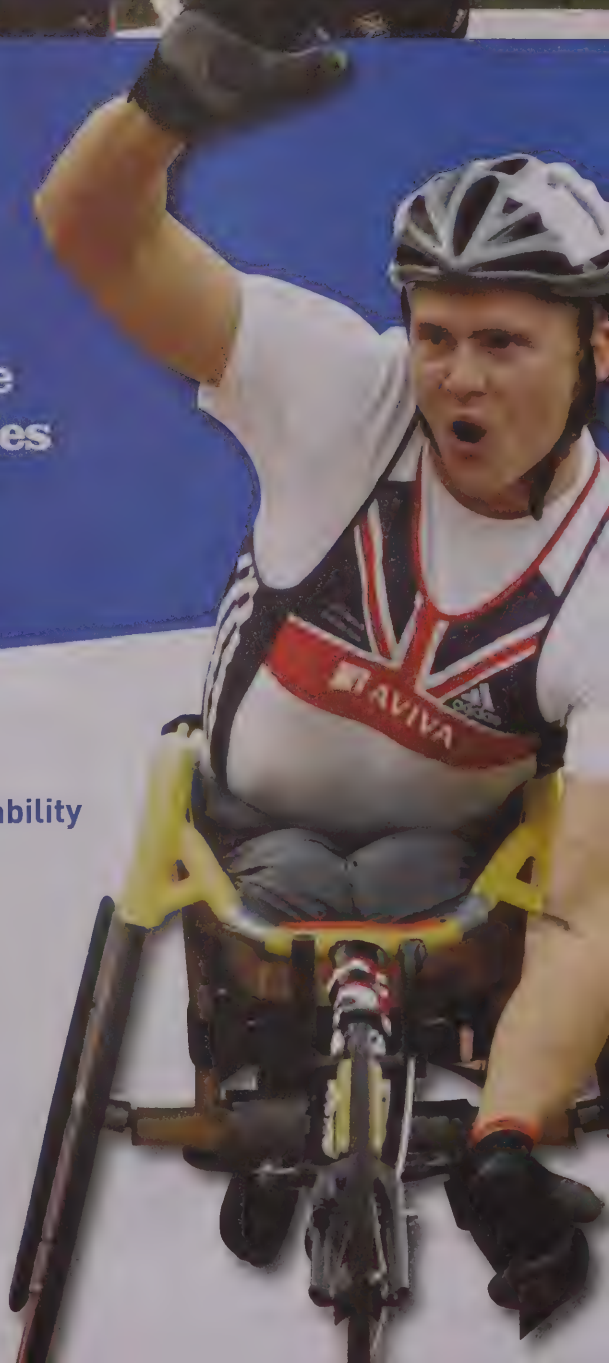
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I'm sceptical of the word "alternative". If you have a disability, you look and live in nonconformist ways and, in this respect, "alternative" is an empowering word, encapsulating individuality.

On the other hand, we live in a world where we often have to take the "alternative" option, which can just be a euphemism for "we couldn't really be bothered" – like when a restaurant has no ramp at the entrance and customers with mobility problems get escorted to the "alternative" entrance, through a maze of dimly-lit corridors and over an assault course of Rentokil boxes and bags of rotting food.

So I went to see if "alternative" in Alternative Fashion Week (AFW), held in London's vibrant Spitalfields Market, stood for positively different, like all disabled people are.

I slinked past the battalion of paparazzi and settled into my centre-front-row catwalk seat (reserved for *Disability Now's* Style Section aficionada) and was demanding my PA fetch me an extra-skinny-double-mocca-latte before I remembered I was neither a coffee drinker nor Anna Wintour.

Watching the show, I was captivated by Wilfried Pletzing's vivid, jewel-coloured collection made entirely from



When we asked our style councillor **Lara Masters** to kit herself out for 50 quid from the high street she almost, in desperation and protest, submitted a photo of herself naked. Will she fare any better with "alternative fashion"

## Lara's other look



vintage sports clothes ([www.w-pletzinger.se](http://www.w-pletzinger.se)). The Swedish ingénue explained: "Working with recycling is challenging. Sometimes it seems limiting because you don't have as much material as you might like. Then you have to find smart solutions or change your plans. Every piece I make is different. There are no rules to follow. I always have to find new ways to work things out. This challenges my skills, my creativity and my intelligence."

"It's very much like being disabled," I interject and Wil nods, hesitantly.

Next, my eyes feasted on a recycled collection by Hayley Trezise whose label, "Raggedy" ([www.raggedyrags.co.uk](http://www.raggedyrags.co.uk)), features rich, vibrant hues and a strong Victorian influence with voluminous shapes, corsetry, bustles, lacing and button details.

Hayley commented; "I design and create recycled clothes using charity shop orphans, and I really enjoy twisting and turning them into something new. It's great buying clothes from charity shops because I'm recycling and a percentage of my work goes to where it's greatly needed. It's eco, ethics and fun, all sewed up together."

Continuing the theme of conscientious consumerism was a collection by Holly



**We live in a world where the 'alternative' option can just be a euphemism for 'we couldn't really be bothered'**

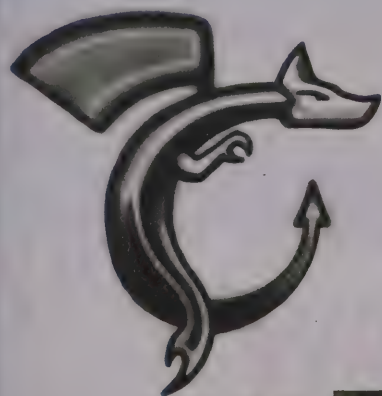
Dutton (<http://sites.google.com/site/bobbiesboutiquesite/>), who is passionate about using sustainable fabrics, after an African holiday led her to question the effects of globalisation on the textile and fashion trades. Organic cottons,

hemp and bamboo mixed with vintage prints create Holly's wistful collection, in soft colours inspired by childhood, dreams, nostalgia and innocence.

Holly is concerned about our irresponsible buying habits. "Alternative Fashion Week is an opportunity to break the stigma that eco and ethical clothing can't be fashionable. When I tell friends I make clothes from hemp, they usually think of scratchy sacks! But my designs show how an eco-friendly garment can still be wearable and creative and

not cost the earth."

My question was answered. "Alternative" in the case of AFW stood for innovation and integrity. Seeing these newby designers' collections gave me hope not only for the future of fashion but for the future of our planet. I also felt there was a kinship between living with a disability and the ethos of AFW. As Wil said: "We aren't working with mainstream trends but inspiring others to live and express their own identity." Out of the mouths of Swedes, eh? Perfect!



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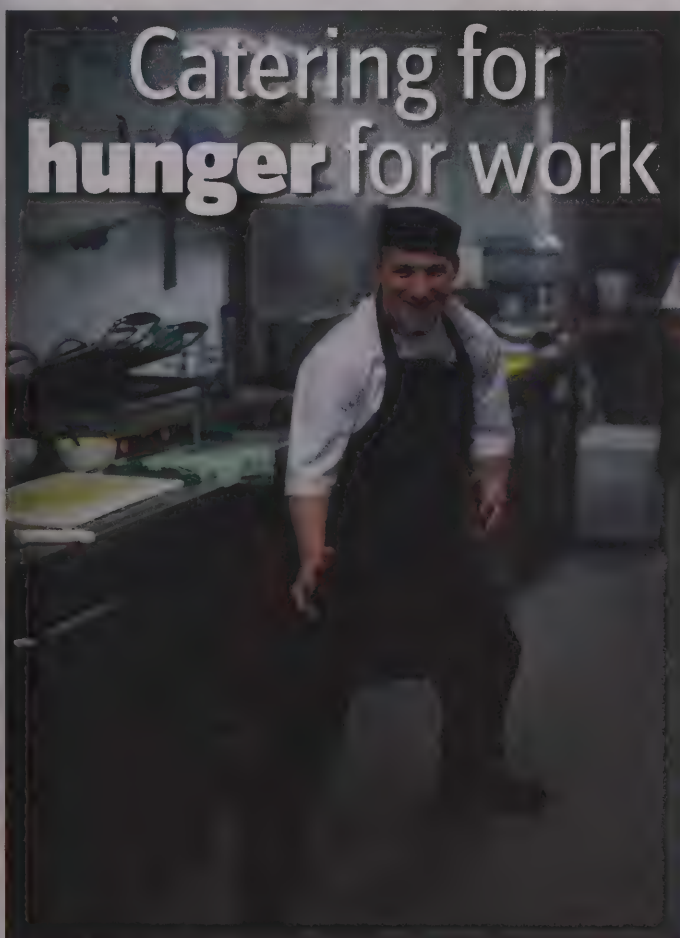
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# localknowledge



Scottish charity Inspire has already helped several people into paid employment through its scheme to help people with learning disabilities into work. It trains people at two social enterprises, the eatery Café Coast and the Inspire conference centre. **Paul Nicoll**, 25, is one of its participants

**M**y ambition has always been to get a paid job in a café or kitchen, but it has been hard because of my learning disability. I found out about Inspire when I visited the job centre and met the disability employment adviser who

told me about the Training for Work programme there.

I started training at Café Coast last year and began working towards a City and Guilds qualification in food and hygiene over the summer. I hope that, once I have finished my qualification in a month or

two, I'll find paid work.

Apart from me, there are five students at the moment with another two about to join. I wanted to learn about catering, but others choose to work in the conference centre, where they might learn about setting up a room. It's up to you to decide what you want to do. Everyone has a different learning plan depending on what their interests and goals are.

My training is supported by the kitchen staff who record what I do every week. I also write work sheets on what I have done. The college come in weekly at the moment to assess us working in the kitchen and they make sure I am working properly.

There is a lot that I have learned about working in a kitchen. I can now prepare egg and chicken mayonnaise, slice haggis and black pudding then box and date it, garnish plates and make sandwiches. I love being in a busy kitchen and seeing people in the café eat the food that I have prepared.

Chef has taught me that the meals we serve should be tasty and look good. When

Café Coast was short listed for the 2009 Scottish Restaurant of the Year award, I felt proud to be part of it.

The programme has taught me other things aside from how to work in a kitchen. I have learned that it is important to arrive on time for work – Chef does not like us being late. I also know now that I must look smart so my whites are always washed and ironed. And I have learned that, in a kitchen, we must all work as a team.

**I love being in a busy kitchen and seeing people in the café eat the food that I have prepared**

My time at Café Coast has given me more confidence. I used to volunteer at a church café before joining the scheme, which I loved, but it was hard to see how it might lead to a job. Having the chance to train in a busy kitchen and work towards a qualification is brilliant. I feel it's given me a great start in finding paid work.

• Paul Nicoll was talking to Julie Griffiths

## → CONTACT US

Do you know of an innovative, small-scale, pilot project, ideally one run by disabled people themselves?

- write to us **Disability Now**, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)



Having enjoyed cheap weekend deals in dozens of European cities before, and after a relaxed break in Budapest last winter, **Cathy Reay** wanted to venture somewhere more vibrant for the teenager in her and historically vital to sate her intellectual appetite

I stumbled across an independent travel group called City Travel Review, whose founders organise trips for young people wanting to see the world and improve their linguistic and written skills along the way. Signing up for their three week spring break, I joined ten other budding journalists on the trip of a lifetime to one of the largest and most culturally significant European cities of today.

Though Germany's famously once divided capital was officially reunited almost 20 years ago with the collapse of the Wall, Berlin's social scene is still affected by the attractiveness of the west and invariably less glamorous east.

There are still some vestiges of the Wall dotted around the city, but most have been or are currently being covered with graffiti and replaced by museums. We were lucky to have been staying in Kreuzberg, just a ten minute walk from the best place to see the biggest single remaining part of the Wall at the East Side Gallery. The Gallery has been turned into a memorial, with many artists from all over the world contributing their representations of freedom along the 1.3km stretch. There are also pieces still standing around Potsdamer Platz and Checkpoint Charlie (the crossing



point between the east and west during the Cold War) in the city centre.

The street art scene in Berlin has exploded since the city's reunification with not only the last bits of Wall being covered by graffiti but also buildings,



**Cathy wasn't impressed with Konnopke's "famous" currywurst**

signs and most outdoor walls. There are a number of art squats around the city, inhabited by graffiti artists who make a living off tourists visiting and buying pieces of their work. The Kunsthaus (art house) Tacheles, in the district of Mitte, one of the biggest, opened in 1990 in a former department store. As you might expect from an old, derelict building, it is far from the most accessible of sites and there are several flights of stairs leading to each floor, but it is definitely worth a visit if you can hack it. Either way, there's a great beer garden and café area in the backyard filled with arty types and the place often turns into a club after dark.

Before visiting Berlin I knew only of the Wall and the Reichstag as important tourist attractions, but there is so much more to see and do that





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# Living off the wall

even after spending three weeks there I still left feeling that I'd not done it all. The city is much bigger than I imagined; it rivals the size of London but with just half the population – something which really comes in handy on public transport, as there is almost always a free seat and no-one hassling you to speed up.

Aside from the large stations, those underground are totally inaccessible

## Tips

Beware crossing roads in Berlin. Apart from the fact that they drive on the other side, cars are allowed to turn corners and drive through red traffic lights if there is no-one visible in their way. Unfortunately, short people like me aren't very visible!

for wheelchairs. Trams, which only run in the east, have a very high step from the ground so manoeuvring onboard was tricky, but not impossible. Most buses have areas for wheelchairs and clear maps and regular intercom announcements make it very easy to navigate once on board.

Our group was assigned the task of creating a travel guide to Berlin during our stay and it was my job to cover food and drink. Fantastic, I thought, I get to drink beer all day and write about it!

Germany isn't best known for its spectacular cuisine, but what it lacks in original recipes is more than made up for in the availability of cheap alcohol, cafés open well into the night and bars that serve brunch at dawn. Because they are hot on recycling, cafés and

shops through Berlin offer money back for every empty bottle handed in. It's common courtesy to drink beer en route to a destination and leave the bottles on pavements for homeless people to pick up and make money from.

We visited a few beer gardens but the best by far was at Café am Neuen See, located on the southern border of the Regents Park-esque Tiergarten. With park benches spread out for miles, people rocking up to play their acoustic guitars and children playing in sandboxes, it has a great atmosphere for a sunny afternoon. The only difficulty is getting to it – the nearest transport link is about 20 minutes away.

While at Tiergarten it's a good idea to check out the Reichstag nearby. Queues for this popular tourist attraction are always long and it's a





good idea to go late at night – last admission is at 10pm. The building is fully accessible and great to walk through, but will only take you about 20 minutes to explore.

In the first week our guides introduced us to a popular Berlin dining tradition, a “fairtrade” café called Fra Rosa, near Rosenthaler Tor. Fairtrade in Germany means you pay exactly however much you feel the staff deserve for their service. Pay 2€ at your own risk, though; those at Fra Rosa thought our group underpaid even though we chipped in about 15€ per person. Fairtrade places try to stay hidden from stingy tourists, which is great, but on the other hand staff are impatient and will expect you to know what to do. They’re also quite demanding (I discovered upon hearing the waitress yell “FLEISCH!” in my face, it’s best just to take whatever “flesh” she gives you). Having said this, the food and wine at Fra Rosa were both of an absurdly good standard, and the buzzing atmosphere of locals getting merry was great too.

After spending a few days eating and drinking ourselves into oblivion, it was time to delve into the city’s history hub. The best place to start is with Museumsinsel (Museum Island), a square of museums on an “island” in the middle of the Spree river. Most places charge entry but you can access any of them for free on Thursday evenings between 6–10pm. The best for Germanic history are the Alt and Neue (old and new) Museums. Others worth checking out are the Museum für Fotografie, Alte

### Tips

If you’re travelling in a group, offer to pay separately in bars and restaurants. Though it takes longer and seems more fiddly, they actually prefer it.



Some of the work on display at Tacheles art squat

Nationalgalerie (I should have picked the rooms I wanted to enter beforehand, it’s exhausting walking through every one), and Pergamon Museum, which houses art displays of Islamic and Middle Eastern origins.

As indicated by the long opening hours and low alcohol prices, the nightlife in Berlin is electric. There are a few main clubs but the focus is more on bars with small dancefloors. Be warned that if you do decide to club it up, you might not get in: we travelled an hour west to Watergate, a big techno club in the classy district of Charlottenburg, only to be refused entry because we didn’t know the DJ’s name. Exhausted and hacked off, we

found a local bar and I had my first taste of Berlinerweißer, a delicious white beer normally served with a sweet green or red syrup. After the sore experience of Watergate, which we aptly renamed Failgate, the group got stuck into the many bars the city has to offer, including a Russian Disco night at Kaffee Burger in Mitte, and free Germanic jazz in Charlottenburg.

It would be easy to put my love for Berlin down to the fact that I was there so long, but I firmly believe that whether you’re visiting for a long weekend or a whole month, there will always be something unique, exciting and educational to do for people of all backgrounds and tastes.





**Tiergarten's beer garden, the largest in Berlin**

It's not the most accessible city in the world, with transport possibly even ranking behind London and many of the streets in the city centre uneven and hard to manoeuvre down, but it isn't impossible to get around. The bars, clubs, cafés and restaurants are similar to anywhere else in western Europe (the bigger the franchise, the more accessible the venue) and museums and exhibitions are generally very accessible to all.

Though I didn't get a chance, it's a great idea to sign up for one of Berlin's walking tours. They're completely free (just pay a small donation at the end) and I am assured that guides do follow any access requirements needed.

It was a fantastic experience to travel with a group of people I'd never met and work on such an exciting project together. Through compromising our tastes we visited many places I would probably never have thought to go and

### Tips

When you pay for most drinks you're also paying a deposit for the container, so make sure you take empty bottles back to shops and return glasses to the bar for some of your cash back.

I felt as though I learned a great deal more about the city than I would if I'd been travelling alone. I also learned a great deal about beer too, but that might not be so useful when applied to my day to day life. ■

- The City Travel Review group runs three Berlin trips a year (winter, spring and a six week summer course) and one in Edinburgh. For more information about them, visit [www.citytravelreview.co.uk](http://www.citytravelreview.co.uk)



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# tried & tested



Publicity for the London Eye and river Thames cruises makes great claims for accessibility. **Sunil Peck** checks out whether they stand up

My trip on the London Eye was dull. But it's no great surprise given that the point of the Eye is to offer views of the city's landscape. But even though I cannot appreciate spectacular views of London from hundreds of feet in the air, I reckon I could derive some enjoyment from the Eye.

I would have enjoyed listening to an audio guide to some of the visible buildings. I would also have been interested to hear about the construction of the Eye whose parts were transported up river by barge so it could be put together.

But the only sounds I heard in the capsule were a couple chatting, the

occasional clicking of a camera shutter and a man standing uncomfortably close to me who threw up five minutes in.

I understand that puking passengers are rare on the Eye so, if you fancy a trip, discounted tickets are available to disabled people, you won't have to queue and staff will stop

the wheel to give you time to get in and out. Each capsule can accommodate two wheelchairs and there are printed guides with information about the landmarks on show.

The cruise along the Thames afterwards on the top deck of a boat was a wonderful sensory experience. There was a stiff wind in my face, the sun was beating down, the smell of boat fuel





© L. SHAT - FOTOLIA.COM

wafted up from time to time and the tunes of the buskers on the South Bank competed with the sound of trains roaring in and out of Charing Cross.

The top deck of the boat is accessible by a lift and induction loops and disabled toilets are available too.

The boat meanders past Big Ben, Parliament and St. Paul's Cathedral while a guide points out other landmarks like a bridge that can clean itself, and locations of scenes in famous films. The audio commentary brings hundreds of years of history to life with tales of a

polar bear from the Tower of London who once bathed in the Thames, frost fairs that took place on the river when it used to freeze over, and a double decker bus which was driving across Tower Bridge when a section of the bridge began to lift into the air to allow a ship

to pass underneath.

Boat trips on the Thames are always a tremendous way of enjoying London. But it's a shame that more has not been done to enable visually impaired visitors to get more out of a flight in the London Eye.

### INFORMATION

To book tickets, use the disabled booking line, Monday to Sunday, 9.00am-5.00pm. Call 0870 990 8886 or email [accessible-booking@londoneye.com](mailto:accessible-booking@londoneye.com)

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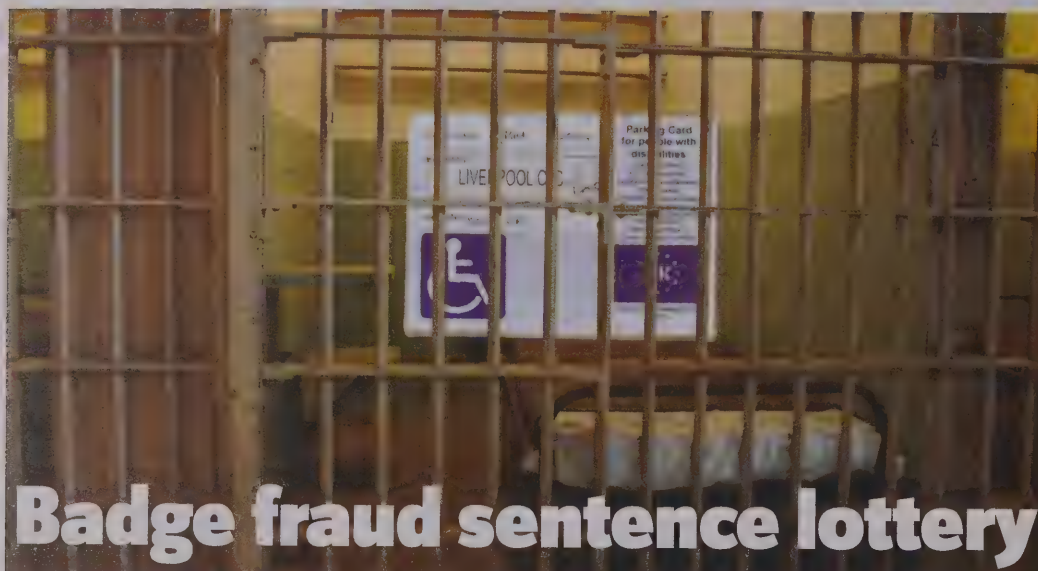
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# roadtest



PHOTOGRAPH: © PATRICIA HOFMEESTER. DESIGN: JAMIE TROUNCE

## Badge fraud sentence lottery



With punishments ranging from light fines to community service orders, **Helen Smith** says it's time that judges got consistently tougher on Blue Badge fraudsters

**Y**ou only have to look at some of the sentences handed out to Blue Badge fraudsters to realise that there really doesn't seem to be any consistency.

Just recently judges at Harrow Crown Court handed down two wildly different sentences to two Blue Badge fraudsters. Faheem Zulqarnain was given a £100 fine and ordered to pay £100 costs while Sahar Vakilzadeh got 40 hours unpaid work and was ordered to pay a £200 release fee for her car and £1,500 in costs. These different sentences have led to criticism from Brent

Council. One councillor said: "Blue Badge fraud is one of the most selfish, inconsiderate traffic offences that we see on our roads, I urge the courts, in every case, to bring down the full force of law on those responsible, sending out a clear message that this crime is socially unacceptable."

But it's not just Harrow Crown Court where the sentences handed down to Blue Badge fraudsters vary enormously. In most courts across the UK judges just seem to hand out fines. These can range from less than £100 to much more substantial sums, as was the case with Osman Sultan

from Ashton-under-Lyne who was fined £1,095 for using a badge on two occasions without the badge holder present.

Occasionally judges impose harsher sentences. Robert Rule from Beechwood, Runcorn was caught using a badge, the expiry date of which had been doctored to show

**I urge the courts, in every case, to bring down the full force of law on those responsible, sending out a clear message that this crime is socially unacceptable**

2009, and was sentenced to 60 hours of unpaid community service. A judge in Peterborough also handed down a three week

driving ban to Sandra Benne who was caught using a Blue Badge belonging to her dead mother. This was hailed as a success by the disabled motorists' organisation Mobilise. Chairman Douglas Campbell said "I think that 21 days without being able to drive is a suitable punishment. I congratulate this judge on the decision he made and I hope to see many more judges following suit."

But it doesn't seem that many judges have followed suit and paltry fines still seem to be pretty much what the average Blue Badge fraudster is likely to get.

In some areas Blue Badge abuse is taken very seriously with Blue Badge enforcement teams employed by local councils. But catching the criminals is just the first step. If all they get is a few hundred pounds fine and they're saving that on parking fees why would they stop? The punishment needs to fit the crime and people need to know what will happen if they're caught. Banning someone from driving takes away their liberty which in effect is what they have done to disabled people. Maybe if all fraudsters lost their licence and had to do community service we'd see less people doctoring, forging, borrowing and stealing badges in the first place.





# Public transport going **nowhere**

**Paul Carter**

A new report published by Muscular Dystrophy Campaign group Trailblazers has concluded that disabled travellers frequently have to pay higher fares to access an "inconsistent and inaccessible" public transport system.

The *End Of The Line* report, used "mystery travellers" to look at over 200 different journeys, with each commuter completing a survey at the end of the trip, as well as collating further feedback from focus groups and blogs.

It found that on up to a third of bus journeys, disabled passengers were unable to board the first bus because of a broken or malfunctioning ramp, while

half of all trains and stations lacked basic facilities for disabled people.

It also claims that disabled people have to pay higher fares to use trains because of the inaccessibility of long distance coaches.

**It's incredible that transport providers think the level of service they currently provide for disabled commuters is good enough**

Trailblazer ambassador, Jessica Berry (pictured, above) said that the report showed there was still "a long way to go" before the transport

system was accessible.

"It's incredible that transport providers think the level of service they currently provide for disabled commuters is good enough," she said.

Grahame Lawson, chair of the Disabled People's Transport Advisory Committee (DPTAC) Personal Mobility and Local Authority Working Group, said that both local and national government needed to do more to meet their obligations under the DDA.

He said: "Despite the introduction of more accessible trains and buses, we agree that it is still often all too difficult and expensive for disabled people to use public transport.

"Spontaneous travel by train is almost impossible for

wheelchair-users. But it is not just wheelchair-users that are affected. People who have sight and hearing impairments have difficulty in using buses outside London because of the lack of audio/visual announcement systems."

Rosemary Bolinger is a wheelchair-user who last year travelled from Eastbourne to Bangor with the new national Freedom Pass to raise awareness of the problems faced by disabled travellers.

She said that the findings of the report "absolutely" echoed her own experiences.

"There are bits that I would add," she said.

"Such as on bus routes that are publicised as accessible, they will quite cheerfully change that without any warning, so you might go into town on an accessible bus because it's marked as an accessible route, and when you go to come back, for whatever reason it's an inaccessible bus."

Transport for All is a body representing the interests of disabled passengers in London. A spokeswoman told *Disability Now* that the findings of the Trailblazers report are common experiences of many disabled Londoners.

She said: "Despite the law and much rhetoric around accessibility, transport services still continue to fail us."



## London Marathon roles reversed



Top three male and female finishers in the 2009 London Marathon: *from left to right, Sandra Graf, David Weir, Amanda McGrory, Kurt Fearnley, Diane Roy, Ernst Van Dyk*

Paralympic champion Kurt Fearnley set a new course record as he ended David Weir's run of successive London Marathon victories.

The Australian emerged victorious by one second after a pulsating sprint finish down The Mall, which bore a striking resemblance to the

conclusion of the 2008 race, although this time with the positions reversed.

On a glorious April day, Fearnley and London-born Weir hit the front early on, along with South African Ernst Van Dyk, and Switzerland's Heinz Frei.

The quartet remained in contention for the majority

of the race, with nearest challengers Denis Lemeunier and Masazumi Soejima almost 40 seconds behind.

Approaching the line, Van Dyk was the racer in pole, but Fearnley and Weir sprinted agonisingly past to take first and second.

Fearnley's time of 1:28:56 took 49 seconds off the

course record, set in 2006 by Weir.

Weir, who was competing in his first race since the 1500m final in Beijing last summer, said his lack of training had been a factor in him not claiming his fourth successive London title.

He said: "It wasn't too



bad a result as I have only been back in my chair in the last two months.

## It's been a hard last four months training but it came good in the end

"I had a break after Beijing and I have had limited amounts of training. All of these guys are doing marathons every other week. I can only do two in a year. At the end I didn't have a little bit extra to fight for the win."

Fearnley said he hadn't been involved in too many marathons "where the finish was that close."

He added: "David was a tough challenger, but I was never going to let him get away with that."

"When it came to the last 200 metres, I kept thinking about the finish and pushed really hard. It's been a hard last four months training but it came good in the end".

There was British disappointment too in the women's race, with Shelly Woods having to be content with finishing

down in sixth position.

In what proved to be another close race decided by a sprint finish, American Amanda McGrory crossed the line in 1:50:39, a second ahead of 2008 champion Sandra Graf.

Despite finishing sixth, Woods was only seven seconds behind McGrory at the line.

McGrory said: "I knew it was going to be a tactical race today."

"There was a pack of six when we started and there were still six fighting it out at the finish."

Canadian Diane Roy, who crashed spectacularly in Beijing, said that incident had played on her mind heading into the London race, where she finished third.

"This is my first time in London and I was pretty scared going into this race after Beijing where I had a crash," she said.

"I was more careful going round the corner today into the final straight. Next time I will be more confident".

Paralympic gold medallist Edith Hunkeler finished in fourth.

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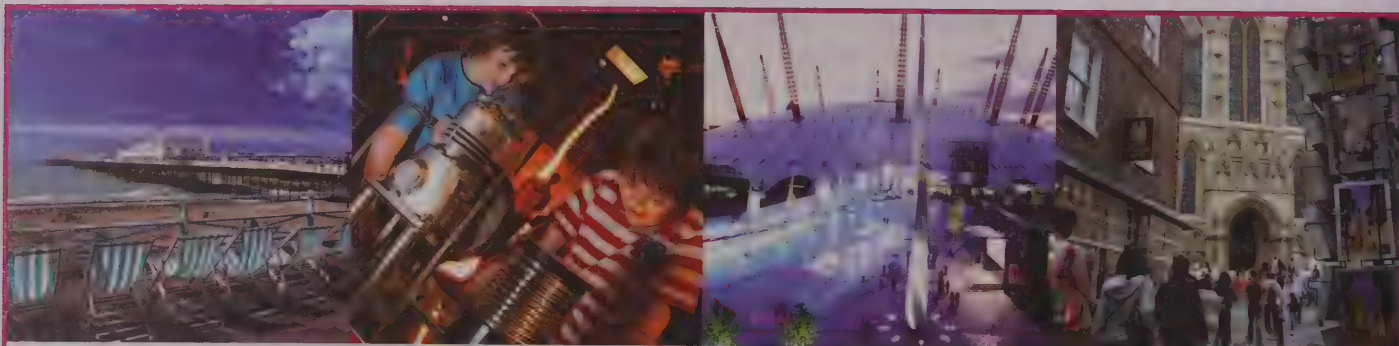
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# entertainmentnow



## Rough Guide still thin on ideas

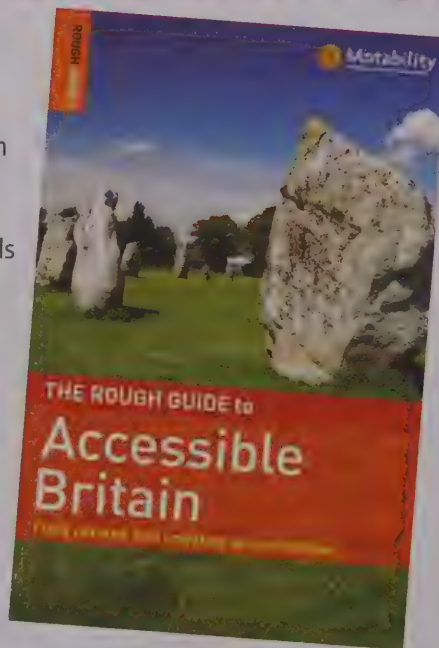
**A**s someone who loves to explore new places, and has taken *Rough Guides* many a time on my travels, I was keen to get my wandering hands on the newly published second edition of *The Rough Guide to Accessible Britain*.

Knowing only too well of the annoyance of going on a day trip only to find a multitude of steps, or that I'd missed out on a disability discount because I'd not pre-booked, I was pleased to find the guide provides thorough factual information on all the destinations and attractions featured. Each listing has contact details, a web address where available, information about discounts, parking and other provisions for disabled people.

The trouble is, well,

there just aren't that many places featured. Anyone reading the guide could be forgiven for thinking that the majority of British tourism is out of bounds for us. What about all the National Trust and English Heritage properties? Seaside resorts and National Parks? The list of omissions is long. The lack of an index at the back of the book also makes it hard to look up an attraction you know the name but not the location of, particularly if, like me, you are prone to being geographically-challenged!

Each chapter contains a wide region – for example 'Yorkshire and the North East' covers the whole of Northumberland, Tyne & Wear, County Durham, North, West and South Yorkshire plus the East



Riding of Yorkshire. In the whole of this chapter only 16 places to go are listed. Having been born and brought up in this region I can think of many, many more – most of which are listed in the regular *Rough Guide to Britain*. Details of accessible restaurants, B&Bs and hotels would have been useful too. All in all, the

guide isn't quite up to the *Rough Guide's* usual high production standards.

Having said that, the guide is a good start and is well worth a look when planning your next weekend break. At the back of the book there's a list of useful contacts for travel advice, information on accessible transport, and British tourism.

Finishing the book I was surprised that although the *Rough Guide's* focus is on accessibility, I couldn't find any information on whether the guide is available in large print or audio format. Something for the publishers to bear in mind when they compile the third edition perhaps.

**Penny Batchelor**

• The cover price is £6.99; the guide is free for Blue Badge holders. Visit [www.accessibleguide.co.uk](http://www.accessibleguide.co.uk) for your copy.



## FESTIVALS

## New stage means Glasto blast

Rob Maddison has been a musician and music producer for almost 20 years. But when he became spinally injured last year he got the usual eye-opener.

"I was shocked to find out that there are far too many music venues that simply don't cater for disabled musos and fans.

"Even if the venue has good access and facilities for the audience, this often does not extend to the back

stage areas.

"So I was very proud to be invited by Attitude is Everything (an organisation that helps champion the rights of disabled musicians and audiences) to play in a showcase for deaf and disabled musicians at this year's Glastonbury festival."

Rob currently plays in two bands – Spaceships Are Cool who're playing the



© VICKY SMITH 2008

Glastonbury stage and Yunioshi who are playing at this year's Summer Sundae and Bloom festivals.

He dares to believe that the Glastonbury stage will

be something of a trail-blazer. "I'm hoping it will prompt other venue owners to become aware of this issue and encourage more disabled musicians to feel they are supported by the music industry in general."

Spaceships Are Cool play the Glastonbury festival DADA stage, in the Shangri-la fields 2pm on Saturday 27 June.

• More info at: [www.spaceshipsarecool.com](http://www.spaceshipsarecool.com)

### → Up-to-the-minute listings

For all the latest arts listings visit  
[www.disabilitynow.org.uk/entertainment/arts](http://www.disabilitynow.org.uk/entertainment/arts)



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# Sussex Health Care

Sussex Health Care is an award winning group of care homes founded in 1985. The Group now operates 16 homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision as well as care for older people.

Sussex Health Care has recently opened 2 new purpose-built facilities:  
**Beechcroft Care Centre, West Hoathly Road, East Grinstead**

for young people with physical disabilities and learning disabilities.

**Horncastle Care Centre, Plawhatch Lane, Sharpthorne, East Grinstead**  
 for young people with acquired brain injury and neurological conditions.

Both homes provide 24-hour nursing care for approx 20 young people in superb purpose-built facilities with track hoisting throughout the homes. Each single room is provided with en suite facilities. A swimming pool and spa pool are available to all service users along with sensory and physiotherapy rooms.



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**HORNCASTLE CARE CENTRE** (Acquired Brain Injury and Neurological Conditions) Sharpthorne 01342 813910

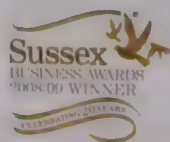
**KINGSMEAD LODGE** (Physically Disabled & Learning Difficulties) Horsham 01403 211790

**NORFOLK LODGE** (Learning Difficulties) Horsham 01403 218876

**ORCHARD LODGE** (Physically Disabled & Learning Difficulties) Warnham 01403 242278

**RAPKYNS CARE HOME** (Adult Care) Horsham 01403 265096

**RAPKYNS CARE CENTRE** (Physically Disabled & Learning Difficulties), Horsham 01403 276756





# webwatch

## The low-down on downloads

Digital downloading is the fastest and cheapest way to access your favourite hits. But, as **Cathy Reay** found, it's not that easy if you're disabled

I love music. I eat it, sleep it, breathe it – and sometimes just listen to it. But over the past ten years the music industry has undergone a serious upheaval and the way we access new material has changed.

Independent record shops have closed down, and Virgin Megastores and Woolworths have stopped making money. The digital revolution is well under way and more and more people are turning to the internet to source music.

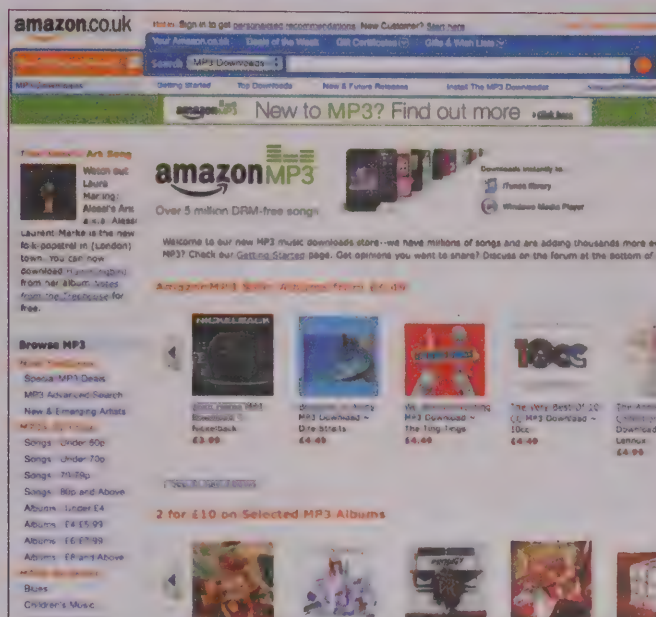
Online shopping is marketed as a stress-free alternative to regular shopping. But for disabled people that's not always the case. *Disability Now* asked Julia Gosling, user interface developer at the web design company Fortune Cookie, to review the accessibility of the leading music e-stores.

The biggest brand name in music software is iTunes, so it came as a huge shock to us to

discover that it's the least accessible of the lot. Julia said: "Using a keyboard (with no mouse), I could bring the store onto the screen and search for a band but I couldn't get into it to preview any music or purchase anything. Navigating the application with a screen reader was confusing too; I wasn't sure where I was at any one time."

**The biggest brand name in music software is iTunes, so it came as a huge shock to discover it's the least accessible**

Spotify, an application that lets listeners stream (but not download) songs for free, is also inaccessible to screen-reader users, Julia said. The colour scheme of the menu is hard to read for people with impaired vision, but the keyboard shortcuts are easy to use.



Last.fm often features free downloads from artists of the day or week and streams songs through the website but the music that starts on each page as you open it is difficult to pause or stop, and it's not possible to make the text bigger, Julia said.

In contrast, the online music store 7digital.com has a good, accessible range of text sizes. Like Last.fm, however, previewing music is difficult to navigate for screen-reader users, who have to return to the top of page to pause or stop it.

The cream of the crop

was Amazon.co.uk. "You can get to all sections using the keyboard, and the music previewer is a toggle on and off, so it's easy to use with a keyboard," Julia said.

"It's the most accessible of the lot, which says more about the inaccessibility of the other sites than the accessibility of this one!"

The inaccessibility of the leading legal music download brands is more than an inconvenience. With many it stops people accessing their main features. Let's hope HMV has no plans to shut down anytime soon.

### → Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)
- phone us 020 7619 7323



# worklife

## Plymouth Sounds

Andy Ballantyne is now a recognisable voice over the airwaves in Plymouth and the south west, on the recently rebranded Heart Radio. He talks to **Paul Carter** about his route into radio

I'm a broadcast journalist for Heart Radio in Plymouth, which means that I'm there to get news stories, produce them, edit them, write the scripts, get the audio and make sure they're ready to go out on air. I also do reading shifts as well, where I read news bulletins. And I'm a freelance sports commentator.

I got into the industry in a bit of a roundabout way, to be honest. I started out doing a broadcast electrical engineering degree at the University of Brighton and, after three years of studying, I realised that there was no way I'd be able to do it 24/7 because of my disability.

What I've got is quite hard to categorise because, as with all these things, they originally thought it was one thing but now they think it's something else. What they call it is Blount's Syndrome, but effectively I'm missing the radius in both my forearms, which means they're a couple of inches shorter than normal, and I don't

have any wrist movement. I was also born bow-legged and had to have lots of reconstructive surgery on my legs and arms.

So, I had to have a bit of a rethink to decide what I wanted to do. While I was having my rethink I was trying to keep the dream alive of doing something in broadcast engineering by doing a few studio jobs and things like that, and I was doing a bit of teaching as well.

Then one day I was in a studio doing a microphone test when someone said I should be on the other side of the microphone because I had a good radio voice.

After various mini-productions and corporate video jobs, I began doing some work with CSV Media, a voluntary group that ran projects to get people from various backgrounds into the media. Through them I got some work experience at the commercial radio station Pirate FM, which was looking for someone to cover sport in the Plymouth area, as the journalist they



had knew nothing about it. I used to go in on a Friday morning, do interviews with team managers and then edit them, all on a voluntary basis, and it just grew from there. Just before the foot-and-mouth outbreak, I was

given a full-time job as Plymouth's journalist.

We've had to overcome difficulties but I wouldn't say there've been any barriers. I've never been turned away or been told I can't do anything.

### ANDY BALLANTYNE: CAREER PATH

- 1997 – Left Brighton University
- 1999-2001 Gained work experience at Pirate FM doing voice-over jobs
- 2001 – Pirate FM's sports editor and reporter
- 2005 – Spent a year in London doing freelance sports commentary
- 2006-present – Journalist for Heart FM



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“People pity him because he is taking care of you... people are reluctant to criticise this saint or to think he could be doing these terrible things.”

*Disabled survivor of domestic violence*



## Disabled women and domestic violence – it's time to take action

Leaving an abusive relationship is difficult enough – it's even harder if you are a disabled woman – especially if your abuser is also your carer.

There is help and support available:

Go to [www.womensaid.org.uk](http://www.womensaid.org.uk) for the **Women's Aid Survivor's Handbook**, available in 11 languages and audio version, as well as the **UK Domestic Abuse Directory**.

[www.womensaid.org.uk/disability](http://www.womensaid.org.uk/disability)

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**WANTED: DRIVE FROM WHEELCHAIR** vehicle. Suitable vehicle required to drive from electric wheelchair. Any vehicle considered. Tel mobiles: 00 353 86 2498607 (Oldtown, Co Dublin) or 00353 86 6044655 (Co Dublin).

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## WARNING

We have been warned about a scam involving people from overseas who say they want to buy a product and who offer to pay using cheques, Western Union money transfers and certified cheques. Although no *Disability Now* readers to our knowledge have been hit by this, please be particularly wary of accepting cheques from overseas. For more information, visit the Metropolitan Police website.



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The Disability Resource Centre

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For an Application pack write, e-mail, visit our website or telephone us.

For an informal discussion contact Mick Dillon, Chief Executive.

We also require a Treasurer to join our Board of Trustees for more information about this voluntary post, please contact us

The Disability Resource Centre, Poynters Rd, Dunstable, Beds LU5 4TP

Tel: 01582 470900 Fax: 01582 470959 Minicom 01582 470968

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## Asthma UK's *Frequently Asked Questions* have been translated into British Sign Language

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People whose first language is BSL can access key information on asthma via signed video clips on our website. A free DVD with subtitles is also available.

The BSL video clips and DVD acknowledge a need for signed health information for deaf people with asthma. You can download our *Frequently Asked Questions*, which are also available in 25 different languages, in Braille, and as an Mp3, via our website at [asthma.org.uk](http://asthma.org.uk)

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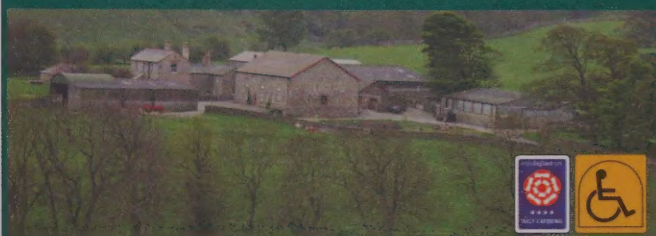
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# backlash



## Alien in an alien world

While pondering why he turns so many heads, **Paul Carter** is also wondering why he's trying to be something he doesn't want to be in a place he doesn't want to be in

**D**ear readers, I think I may need help. You see, in the latest move in my seemingly never-ending quest to become The Very Person I Despise With Every Atom Of My Being, I have edged one step nearer to middle-class mediocrity and joined a gym.

And not just any old gym either, oh no, I couldn't do that.

This isn't one of those places that in my day used to be called a "leisure centre", where staff had to put tablets in the swimming pool to tell if anyone peed in it.

Oh no. This is one of those unbearably smug places where entire families arrive en masse in fleets of armour-plated 4x4s, all dressed in matching tennis outfits and clutching custom made racquets made out of silicone graphite.

Moving a step closer to becoming The Person is, however, in this instance at least, a necessary evil, largely because in recent weeks I seem to have developed what can only be described as a rather unattractive waddle.

Add to that the fact that



**“Yuppies on their running machines practically fall over themselves in amazement every time they see me walk by”**

if my waist size continues to expand quite so exponentially, then I risk sucking small items that I might pass by into my own orbit, then maybe you can understand my reasoning – please understand my reasoning, you're all I have!

The biggest problem I have with gyms (or health and

fitness centres as their pretentiousness would have it) is that they are quite possibly the most alien environments for a disabled person that you are ever likely to find. It's truly bizarre.

Me walking around in the gym seems to attract an inordinate amount of attention from people who would not normally bat a Rimmed eyelash. Add to this the fact that any notion of social propriety seems to be thrown out of the window, as yuppies on their running machines practically fall over themselves in amazement every time they see me walk by. I have to

say, it's most amusing. Next time I happen to go, which judging by my current record might be quite some time, I quite fancy taking a walk through the weightlifting area to see what mayhem I can wreak purely with my presence.

It's quite exhausting; I didn't think that lamely attempting to shift a beer gut could attract quite so much attention.

Anyway, my ultimate aim for joining is to become buff, so by the time you read this next month I might be too muscle bound to type. Chance would be a fine thing.





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There's a large section for disabled people covering:

- ➔ home and housing
- ➔ financial support
- ➔ disability rights
- ➔ employment
- ➔ health and support

Find out about equipment, adapting your home or vehicle, direct payments (arranging your own care and services), social care assessments, the Blue Badge parking scheme – including an interactive UK-wide map, travel and transport, accessible technology – and much more.

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Flexi-seat  
seating system



\*Calls from UK landlines are free of charge, calls from mobile networks may incur additional charges, please check with your telephone provider for details.